

**Navigating Evidence-Based Practice:
A Presentation for Parents and Caregivers**

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Abstract

Prevalence rates for children with Autism Spectrum Disorder (ASD) have increased dramatically, to the current estimation of 1 in 68 (Centers for Disease Control and Prevention [CDC], 2014). The overall intention of this project is to develop a workshop for families, and caregivers, which will enhance awareness, the importance of evidence-based practice for individuals with ASD and provide local resources that are available. This project involves a literature review of ASDs, evidence-based practice (EBP) and how it affects both families and caregivers. The literature review attempted to answer the question, what are the most popular evidence-based practices and what are the benefits in parents understanding EBP for children with ASD that are currently being utilized today. The purpose of this project is to assist families and caregivers in making well-informed decisions involving the choice of treatments that will have the most positive impact on their children with ASD.

Keywords: Autism Spectrum Disorder, children, treatments, evidence-based practice

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This has been quite a journey as part way through my MRP my dad became ill and I took a leave from school. It is only through the love and support of my husband Brian, my children, Meghan and Julia, that I was able to continue. You were all my rock when I needed you most. I love you.

I would also like to express my sincere gratitude to my family and friends: thank you for supporting me, listening during both the good times and the bad, sharing my stress, and being there when I needed you most. To my mom, sister, and brother, you have shown me love, support, and encouragement through every choice I have made. This year has been extremely difficult for all of us and we will persevere together.

Finally, this project is dedicated to my dad: you are my hero and I miss you more than words can express.

PROLOGUE

My Story

“Where’s your Mom?”

“Dad, Nana broke her hip and you drove them to the hospital, remember?”

“Oh that’s right.”

10 minutes later.

“Where’s your Mom?”

I will never forget the fear I felt at that moment. I had no idea how much our life would change over the next few months.

“It could be dementia you know,” the emergency physician whispered.

“Onset suddenly like this?” I asked.

“Yes,” she said.

Two days later we were back in emergency department. It was December 31, 2013. We spent the next 24 hours in the emergency room and my dad was admitted the next day. I did not begin to imagine the hurdles we would have to experience or how to navigate a system where we had lack of support and resources. During the next week, his mobility continued to decrease and he was experiencing short term memory loss. His personality was markedly different; he had lost the laughter and joyful easiness we once knew. After a week of tests, all of which came back clear, physicians sent us to specialists who dismissed our concerns and believed he had early onset dementia. With feelings of sadness and shock, we were referred to a geriatrician but we still had so much uncertainty revolving around the referral. We were sent home and they said they would call us with an appointment time.

From that day forward we created a daily journal in which each of my dad's symptoms was dated and classified (although no one on the medical team seemed to notice or recognize the need for such documentation). We found ourselves fighting for a diagnosis while enduring long wait times. We had no support in place for his declining health at home, and we had no idea what was wrong. Whatever disease or illness my dad had, it was always one step ahead of us. He needed almost 24-hour care. After our family physician concurred that this was not dementia, we were urgently referred to a neurologist who told us he promised to help us find out what was wrong. Inevitably, we received the devastating news: my dad was diagnosed with sporadic Creutzfeldt-Jakob disease (CJD). The sporadic form (which means it occurs for no known reason) is the most common form of this very rare (one person in every million worldwide is affected) and terminal disease. It was almost exactly 14 weeks after that very first moment, when my dad forgot where my mom was, that he passed away. My father was still at home.

Giving my dad's eulogy, I thought speaking was the most difficult thing I would do, but, as I am writing this, I realize that there will be many more hurdles still to come. Now that I have first-hand experience, I understand why families look for cures or treatments in a desperate attempt to help and/or find a cure for a loved one. I am still frustrated with our system. I am angry at the way we were treated by some health care providers. However, I am also conscious of the compassion and helpfulness of other professionals who assisted us through our tumultuous journey. Anyone can be that one-in-a-million.

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CHAPTER ONE: INTRODUCTION TO THE STUDY

This project reviews the benefits for families by utilizing evidence-based practice (EBP) for their children with Autism Spectrum Disorders (ASDs) in order to make informed treatment decisions. It is through my own personal story that I developed a deeper understanding and empathy for families as they struggle to make the connection between EBP and ASD. I have used my own personal and professional experiences to create a workshop that assists families of children diagnosed with ASD to circumnavigate a complicated system, including understanding the advantages of EBP and how it particularly relates to ASD.

My experience has transformed me as, a mother, wife, student, as well as a professional. I now have more insight and understanding for families whose lives also have been altered by something beyond their control. I can now identify with the anger and the confusion that comes when all of the papers are piled in front of you with professionals saying, “What don’t you understand?” and “Why can’t you fill everything out?” Through my personal experience, I have learned that everyone has a story, and that no matter what situation you are in or what the diagnosis is, it will be a journey. I want to help families to know that their story is important. This workshop will provide local resources and guidance on how to navigate EBP in ASD.

Background of the Problem

Over the past 15 years, prevalence rates for children with an Autism Spectrum Disorder have increased dramatically in Canada and throughout North America to the current estimation of occurrence of 1 in 68 births (Centre for Disease Control and Prevention [CDC], 2014). Autism Spectrum Disorders (ASDs) are multifaceted, neuro-developmental disorders that are life long (Szatmari, 2010). According to the American Psychiatric Association (APA) (2014), the severity of symptoms across the autism spectrum can differ markedly from one child to another.

Children with ASD exhibit a range of challenges across several significant areas of functioning that can cause difficulties with social interaction, social communication, and unusual and/or repetitive behaviours.

For parents, having a child receive a diagnosis of ASD can create a mix of emotions, which includes anxiety, uncertainty, stress, vulnerability, and feelings of isolation (McDonald, Pace, Blue, & Schwartz, 2012; Weiss, Wingsong, & Lunsy, 2013). As there is an increase in the number of children being diagnosed with an ASD, there are also a multitude of new treatments that are becoming available. Diagnosis can be an excruciating and difficult time for families, especially when they are trying to locate and access resources, as well as understand all of the different treatments that are available (Strunk, Pickler, McCain, Ameringer & Myers, 2014). Some of these treatments even make the astonishing claim of a possible cure for ASD, while other treatments may charge families thousands of dollars with the promise of improvement in the outcomes for their children. It is therefore imperative that professionals provide accurate and relevant information to support families in their decision making in order to ensure optimal outcomes for their children.

Statement of the Problem Context

Currently, there is media frenzy around which interventions are beneficial for families of children with ASD. Deciphering what information is accurate is an arduous task, especially because media tends to report trends rather than evidenced based research (Ryan, Hughes, Katsiyannis, McDaniel, & Sprinkle, 2013). Filtering through the numerous methodologies and determining the strategies best suited to the individual needs of a child with ASD can be overwhelming and confusing. Due to the growing numbers of children with ASD, it is important to ensure that families understand the importance of evidence-based treatment methods since

research has shown that the use of EBP has improved outcomes for children with ASD (Marder & deBettencoup, 2015). Evidence-based strategies and methodologies, unlike media reports, however, are published in peer reviewed journal articles, which are not accessible to the general public due to readability and paywalls (Mackintosh, Myers, & Goin-Koche, 2006). Media is written for the general public and is meant to be easily understood without obscure terminology, whereas empirical articles use specific terms, data, and academic language that can be difficult for untrained people to interpret.

Currently, there is a reported increase in the anti-vaccination movement even though findings from a recent study supported that the “MMR vaccine is not associated with autism” (Maglione et al., 2014, p. 334). Unfortunately, due to their influence and fame status, celebrity endorsements of controversial bias and/or treatments can also cause confusion among families. One example of such celebrity influence in ASD awareness is Jenny McCarthy. McCarthy has used her fame, as an actress, to suggest to families and the public that her son is cured of ASD, while researchers continue to pass along the message that it is a life-long disorder. She has also been very active in a movement to eliminate vaccinations. McCarthys’ insistence that her son was cured, in part by the use of biomedical treatments, may provide parents with false prospects that could be detrimental to the needs of their own children with ASD, as well as to their own emotional state (Yochim & Silva, 2013).

Purpose of the Study

The purpose of this project is to assist families of children with ASD to develop a better understanding of EBP and how to choose reliable treatments that will provide the most optimal outcomes for their children. My project will focus on defining and navigating evidence-based practice (EBP) in ASD. I will create an interactive workshop derived from my literature review

that will assist with knowledge translation so that parents/caregivers gain a better understanding of the importance of selecting scientifically proven treatments that will lead to the more positive outcomes for their children with ASD.

Rationale

In my role as an ASD consultant, I am frequently approached by families, educators, and community service workers who are looking for different treatments and strategies to assist with managing some of the difficult behaviour their children with ASD may display. Families have to contend with long waitlists to see physicians, funding obstacles, and an intimidating and vast list of treatment options. Treatment choice is dependent on various factors making the parents' choices complex, which can cause additional stress for all family members (Strunk et al., 2014). At this stage in the current research, there are few resources created specifically on EBP and ASD for families. The ones that are available are offered through National Autism Center (NAC) and another through the National Autism Professional Development Center (NPDC) on Autism. Both organizations have websites that provide information and resources that can begin to help increase the knowledge of best practices for parents/caregivers. Research supports the use of the internet as a meaningful resource for families for finding information on autism (Green et. al., 2006). The first source of information, according to Mackintosh, Myers, and Goin-Koche (2006) is parents speaking with other parents of children with ASD, and then books and websites, instead of turning to professionals—this form of knowledge acquisition has huge implications on the possibility of wrong information being received.

I created this project to enhance awareness about EBP, and ultimately help families understand why it is valuable. This learning is provided through a facilitated workshop, where families can have the opportunity to express questions and concerns that they may have about the

material. According to Reichow et al. (2011), on-learning may appeal to individuals who are driven by more self-directed learning, where as face-to-face workshop will allow families to pursue a variety of other educational opportunities. There are several reasons why face-to-face learning may be valuable: (1) it will allow families to meet other families facing similar obstacles; (2) it will provide consistent communication, clarify terminology, and offer the opportunity to develop and answer questions; and (3) it will also help optimize learning since choosing which treatment to use is not as straight forward as research presents it. Clinicians cannot make independent decisions as they also have to take into account the needs and strengths of the child, funding obstacles, and family beliefs and values, as well as propose realistic expectations of families' time, stress, and energy. This project will outline and define several different interventions that I have found to be essential for sound programing practices for children with autism, both in my literature review and within my own practice.

Objectives

1. To assist families, parents and caregivers to have access to reliable and effective treatments for their children with ASDs.
2. To coordinate multiple resources and organize information in a concise manner.
3. To promote the use of evidence-based practice.

Scope and Limitations of the Study

There are several limitations to my project. One, since I am not completing a research study, I can only provide information. The next step of treatment strategies must be left up to families and professionals to implement (or to share resources about) and therefore this project is not outcome based. Additional limitations are possible due to individual family circumstance,

such as transportation, (funding for) childcare, and language barriers. There is no program evaluation other than the reviews I include from different professionals.

Outline of the Remainder of the Document

All of the findings and research making up this project are divided into five different chapters. Chapter 1 seeks to introduce my workshop and resources, while Chapter 2 contains my literature review of EBP and includes the four top treatments I have chosen to examine in my presentation. Chapter 3 reviews the need for the product and the process of building the workshop from the literature review, as well as outlines the methods used to format my workshop. Chapter 4 includes the ULR to my interactive workshop created in Prezi and the complete workshop in the format of a facilitator's guide intended for the ASD Clinician that will be facilitating the workshop. Please note that this is not an intended to be a stand-alone presentation. Finally, I conclude with Chapter 5, where I present a summary of the project by articulating the key learning outcomes, identify the recommendations from the reviewers, and provide implications for future research.

CHAPTER TWO: LITERATURE REVIEW

Chapter 2 provides a review of the existing literature on ASD and EBPs that will be used to help develop the workshop *Navigating Evidence-Based Practice: A Presentation for Parents and Caregivers*. Evidence-based practice (EBP) has become increasingly more important in the field of ASDs (especially as the prevalence of ASD diagnoses has increased). In the 1970s, the medical field began to embrace EBP, which then expanded into many other fields, including education (Cook & Odom, 2013). Upon reviewing EBPs, the chapter continues to explore the most utilized evidence based strategies when working with children with an ASD.

Evidence-Based Practice

Researchers define EBP as interventions that have scientifically been proven through rigorous experiments, and, when delivered successfully and appropriately, the results of the treatment generate a positive outcome for the child with ASD (Children's Mental Health [CMHO], 2003; Mesibov & Shea, 2010; Cook & Odom, 2013). Children's Mental Health of Ontario (2003) supports the notion that "experimental, quasi-experimental or single-subject research designs that have been peer-reviewed in professional journals and replicated several times before it can be deemed evidence-based practice" (p. 22). Autism Spectrum Disorders are receiving an excessive amount of media and public attention today, which makes it pressing to rule out unreliable treatments that may hinder or possibly even harm the progress of our children with an ASD (McDonald et al., 2012). Media can be inclined to report current trends in treatment, regardless of the scientific research that may or may not support their use (McDonald et al., 2012). There are immeasurable amounts of treatments and strategies to be found on the internet, in magazines, in the tabloids, and other popular media venues. Unfortunately, not all treatments are created equally, and not every intervention will be appropriate for each child—they must be individualized in order to be successful. According to the National Autism Centre's (NAC) National Standards Project, Phase 2 (NSP2), there are some documented treatments that are even harmful to children with ASD.

It is therefore crucial for professionals, families, and educators to become skilled learners and have the means to determine which strategies and interventions are evidence-based, reliable, and safe. McDonald et al. (2012) suggests that there could be a lack of scientific information about ASD, which can then make it hard to resist trends and unfounded perspectives that are being presented through the media as a cure. One example of why EBP is so significant is the

case of the Craven family, whose two sons were both diagnosed with ASD. According to Kalb (2005), the Cravens spent over \$75,000 in treatments in just one year and have “tried a dizzying array of therapies: neurofeedback, music therapy, swimming with dolphins, social-skills therapy, gluten-free diets, vitamins, anti-anxiety pills and steroids” (para. 2). Another family, the Dolces, reportedly paid \$2500 for an assessment through an osteopath who prescribed vitamins, a wheat- and dairy-free diet, along with a very controversial treatment of chelation therapy, a medical procedure removing heavy metals from the body (Kalb, 2005). Although the family was informed that scientific studies did not support chelation therapy, even stating that there was a possibility of serious side effects such as liver and kidney damage, they participated in the treatment. The Dolces say they considered chelation therapy because they were willing to try anything to help their child (Kalb, 2005). Families can potentially lose thousands of dollars paying for treatments or even trying controversial therapies that have been scientifically proven to harm their child in the hopes of obtaining a miracle cure. Collaboration between families and professionals is critical—we must work together to meet the needs of children with ASD and develop a better understanding of the importance of EBP.

Another concern in the field is that not all service providers and educators are trained in EBP (Cook & Odom, 2013). To date, there have been only a few comprehensive studies that have reviewed all the behaviour and educational treatments that are available for individuals with an ASD. There are two that have been specifically designed for parents: one by the NAC and one by the NPDC. In 2015, the NAC released phase 2 of the National Standards Project (NSP2) in hopes that it would continue to update research and to help guide all health care professionals, families, and educators in making informed, evidence-based decisions when deciding what treatment to use when working with children with an ASD. The NSP2 has defined ASD

treatments as being: established, emerging, un-established, and ineffective/harmful. They found that there are 14 established treatments to date, which have been “confidently determined that a treatment produces beneficial treatment effects for individuals on the autism spectrum” (National Autism Center [NAC], 2015, p. 41). As it has already been noted, new interventions are being proposed all the time and need to be put through the same rigorous standards and testing of established treatments. Unfortunately, this process takes time, so we cannot rule out emerging treatments even though there is need for more study (NAC, 2015). As children with ASD have difficulty generalizing information and strategies across environments, it is essential to have the collaboration of service providers, school personal, and families/caregivers imperative in order to effectively implement strategies across all contexts.

Our main goal of treatments as a service provider is to use evidence-based interventions to ensure that we are maximizing the independence and potential of a child. Some research has claimed that only one particular model should be followed in order to be successful, for example either Applied Behaviour Analysis or Structured Teaching (Hundert, 2009; Mesibov & Shea, 2010). Alternatively, new research suggests that that perhaps a combination of interventions needs to be used when working with children with ASD (Callahan, Shukla-Megta, Magee, & Wie, 2010). Integrating a variety of individualized evidenced-based strategies can complement each other when they are based on a child’s strengths and needs. This will lead to the development of treatments that will promote the best outcome for our children. It will also help to minimize problem behaviors that we can see within the three core areas of deficits. Two core deficits of ASD have been social and behavior challenges but there are other characteristics that must be noted. Children with ASD can also have difficulty with attention, impulsivity, aggression, sleeping difficulties, self-injurious behaviours, tantrums, and more. The use of a

comprehensive multidisciplinary approach, which includes having the child and family at the center of the team, is the ideal goal. I believe it would be detrimental to the needs of our students with an ASD, and all learners, if we only focused on using one method exclusively.

I am going to highlight some interventions where research has demonstrated evidence of success. It is important to remember that the following is not an exhaustive list of treatments; I have chosen them because they are the most utilized, both in my own experience and within the education system and ABA practice. According to Mesibov & Shea (2010), visual supports, principles of applied behaviour analysis, and principles of structured teaching, are the most visible and frequently cited interventions used for working with children in schools, by service providers, and even parents/caregivers. The following treatments have been proven by the NSP2 (NAC, 2015) to be either established or emerging:

1. Applied Behaviour Analysis (ABA)
2. Visual Supports
3. Social Scripting
4. Structured Teaching (ST)

Applied Behaviour Analysis (ABA), visual supports and social narratives and scripting were considered established EBP, while Structured Teaching (ST) is still considered to be an emerging treatment. However, recent literature does support the latter treatment effectiveness (Callahan et al., 2010; Heflin, Hess, Ivey, & Morrier, 2008; Hume, Loftin, & Lantz, 2009), which demonstrates the importance of staying abreast of current research.

Applied Behaviour Analysis (ABA)

Applied Behaviour Analysis (ABA) is a scientific approach to understanding behavior and how this behaviour is affected by the environment (Hundert, 2009). According to Matson et al. (2012), ABA has been used as an effective intervention to understanding and changing behaviour in the field of ASD for many years. ABA contains many different types of strategies that can be used successfully within home, health care, and school environments. The strategies, based on ABA principles, are chosen by the service provider and matched to the specific needs of the child. Data collection of each outcome ensures the effectiveness of the strategies (Dunlap, Huber, Iovannone & Kincaid, 2003). Principles of ABA have also been used to help teach new skills and assist with the generalization of skills into different environments, which is difficult for children with autism (Hundert, 2009; Ontario Ministry of Education, 2007). Hundert (2009) believes that, through the principles of ABA, one can either increase or decrease desired behaviours and/or skills. While many ABA strategies are being used at home and in classrooms, service providers and caregivers are not always aware that they are already using them. Some common examples of ABA strategies are: modeling, reinforcement, task analysis, forward chaining, backward chaining, and shaping (Hundert, 2009). It is important to remember that when a service provider is using any evidenced-based strategy or treatment, it requires professional judgment, continued assessment of child's strengths and needs, as well as collaboration with parents and/or other professionals (Cook & Odom, 2013).

Visual Supports

Children with ASD may have difficulty processing auditory input and may also miss many verbal and gestural cues. Literature both supports and suggests that individuals with ASD “learn more effectively through the use of visuals rather than auditory information” (Mesibov &

Shea, 2010, p. 573). According to the Ontario Ministry of Education (2007) visual supports can provide a variety of functions for a student with ASD, such as: making sense of information through schedules, assistance with learning, augmentative communication, task analysis, and assisting with the prevention of problem behaviours (Arthur-Kelly, Sigafoos, Green, Mathisen, & Arthur-Kelly, 2009). Since auditory information is very transient, it forces children with ASD to rely on their memory alone to recall the information, which is difficult (Ontario Ministry of Education, 2007). Visual supports, alternatively, are static sources, which allow the child to keep the visual in their working memory while providing an opportunity to refer to the information for as long as needed. It is up to the professional working with the child with ASD to determine through assessment what information needs to be presented visually in order to provide the child with the greatest benefit. This process requires an assessment of the child's skill level to determine the format the visual should take so that the appropriate support is put in place. There are different levels of representation that a visual can take and this will depend on the needs of each child. Research by Meadon, Ostrosky, Triplett, Michna, and Fettig (2011) proposes that a student with autism may use one, or a combination of, the following from the hierarchy of visuals:

- Objects (real, partial, miniature)
- Photographs (colour, black and white)
- Picture symbols or line drawings (colour, black and white)
- Words

Visuals should always be accessible and available to students with autism, especially if the student is non-verbal and has no other forms of communication. Visuals supports can also be used to help a child with ASD to understand and complete the task required independently

(without adult support). It also provides an avenue for communication for students with autism who have difficulty, or even an inability, to communicate their needs and wants through conventional methods.

Social Narratives and/or Social Scripting

According to the National Standards Project (NAC, 2015), social scripting and narratives are an “established” intervention that can be used to help support individuals with autism in developing both functional and successful social interaction skills. Social narratives are intended to assist children with ASD to learn control their own behaviour. The narratives explain different social situations for the child and will help cue them on how they should respond in certain situations (Balfe et al., 2011). This is a visual strategy that can be reviewed prior to any transition, new situations, or one that can be implemented pro-actively to help reduce any interfering behaviours (National Professional Development Center, 2010). Social scripts are more basic than the aforementioned social narratives. A social script provides a child with directions on what they can do or say in specific social situations (National Professional Development Center, 2010).

Example of a Social Script:

What I Will Do When I Go to Tim Hortons

Many people like to go to Tim Hortons.

Sometimes I may have to wait in line before I can order.

That is okay. I will get to order my hot chocolate soon.

I will use my words to ask for HELP when I need to order – or – find a seat.

I will say-

“I need HELP to order” – OR

“I need HELP to find a seat, please.”

Social narratives and scripts are interventions that do not take a lot of time to create, are not intrusive, and can be implemented within naturalist environments. They are also individualized in order to meet every child's unique needs and can be put into a variety of different formats, including photo, line drawings, and words, and paired with audio output or video output.

Structured Learning Environment

Structured Teaching (ST) or a Structured Learning Environment (SLE) was developed by Division TEACCH (Treatment and Education of Autistic and Communication related handicapped Children) at the University of North Carolina. Structured learning environments have changed across the decades and is can be defined as a way to match individual treatments with the neurological differences that are found in ASD (Mesibov, Scholpler, and Shea, 2005). TEACCH aims to improve “both social interaction and communication by means of a specially created environment in which the child with autism can function and through a specially adapted teaching approach” (Powell, Thornton, & Tutt, 2006, p. 76).

The main principles of a Structured Learning Environment (SLE) according to Mesibov et. al., are:

- Physical organization of the environment
- Individualized schedules
- An activity system to help promote independence
- Visually based materials and learning activities

It is through these combined strategies, referred to by the NSR as Structured Learning Environment, that teachers/parents look at modifying the environment and students with ASD receive instruction with an emphasis on information provided visually and with “external

organizational support” (Hume & Reynolds, 2010, p. 228). By utilizing these combined strategies, parents, caregivers, and various professionals can ensure that children with ASD receive instruction with an emphasis on visual information and modifying the environment with ecological supports. The National Standard Project (NSP2, 2015) views Structured Learning Environments as an emerging treatment but there are some strategies embedded in its principles that are already evidence-based.

CHAPTER 3: PROCEDURES

The purpose of this chapter is to outline the process that was involved in creating this workshop. This chapter will discuss the need for the product, the process of development, implementation, evaluation and revision criteria. The ULR for the workshop and facilitators guide is presented in Chapter 4. This project will provide a means to make professional development and education readily available to parents/caregivers regarding best practices (Addison, Contrucci-Kuhn, Lerman, & Vorndran, 2004).

Need for the Product

Autism is one of the fastest growing developmental disabilities today, which implies that the knowledge base of EBP for professionals and families will continue to evolve (CDC, 2011). As research indicates, interventions must meet the need of the students’ specific characteristics of ASD (Goodman & Williams, 2007; Hume & Reynolds, 2009; Szatmari, 2010). In order to support children effectively, we must stay apprised of new research pertaining to treatment and interventions. If we can begin to assist families/caregivers to understand the importance of critically evaluating interventions, then we can provide them with current, accessible information to help navigate a never ending array of treatments (Children’s Mental Health Ontario, 2003). Otherwise, if we do not help families to discriminate between effective and unsubstantiated

strategies, they may find themselves in a similar situation to Dana Craven, where they will continue to “try just about anything if it makes sense” (Kalb, 2005, para. 3). The workshop will teach families how to understand treatment choices and help them make informed decisions when selecting interventions, resources, and community agencies.

Process of Development

Initially, I completed a comprehensive literature review to determine the most promising and utilized EBPs for working with children with ASD. I was able to locate and reference over 40 different articles and some evidence-based websites. To locate journal articles, I used the Pearl Harvesting information retrieval framework, which was accessed through a Wiki site created by Robert Sandieson (n.d.). This site pulls out the key phrases to assist in making a systematic search for EBP and ASD. The search was limited to literature that was available online and published during or prior to 2004. While finding reputable web-based resources was more difficult, and there is not a great deal of research published around websites (Reichow et al., 2011), I needed to be aware of the national organizations and resources that advocate for and use EBP. I reviewed the sites and engaged in discussion with my reviewers regarding the pros and cons of each site. I also ensured the sites were parent-friendly. Through both comprehensive discussions and feedback from the reviewers of my presentation, it became evident that a stand-alone document may not meet the needs of all families. As the learning styles of adults needed to be taken into consideration when creating the workshop, a multi-dimensional approach was used. According to Murphy, Trembath, Arciuli, and Roberts (2011), when resources and workshops were combined with facilitation, families reported they felt more confident and had more knowledge regarding EBP. By completing a thorough article review of specific EBPs, the areas of focus for the workshop can be justified as important areas within this field of study.

I believe it would be detrimental to the needs of our students with an ASD, and all learners, if we only focused on using one method of EBP exclusively. Professionals must continue to assist families in finding a variety of methods that meet the unique learning needs of all their children, while researchers need to recognize that these strategies are not “mutually exclusive” (Callahan et al., 2010). Integrating a variety of individualized strategies based on a student’s strengths and needs leads to the development of programs that promote the best outcomes for students with an ASD. The purpose of this review was to bring awareness of the importance of EBP and the difficulties families have understanding and accessing support for themselves and their children.

As previously discussed, research demonstrates that parents turn to the internet most often for researching treatments. This is why I have chosen to use Prezi, a free online presentation tool. Families can access it through their own computers, iPad, tablet, and/or at their local library. It is recommended, however, that families first attend a facilitated presentation, from which they will be sent home with the portable interactive session that includes information about local resources and supports. These resources, which are hyperlinked throughout the presentation, make information around EBP, reputable websites, and other additional ASD community supports easily accessible for families.

Implementation and Evaluation

The pilot testing was completed by a parent, Behaviour Therapist and Psychological Associate. They provided reviews of the workshop:

- Great presentation Michelle. Very informative. Is it primarily for families with newly diagnosed children? Above all I think that parents need to know that advocating for their children can be a challenge at the best of times but not to get discouraged. They are the

one voice that will be constant in their kid's lives. Reaching out to the various supports and organizations is imperative. Parents should also seek support for themselves. I wish I had.

- EBP in ASD, captures the sense of navigating the journey of living, understanding and managing and treating a diagnosis that affects the lifespan of the individual. It uses the personal perspective of individuals with a diagnosis of ASD as well as the personal experience of the author who has had to deal with trying to understand a complicated diagnosis in a loved one to engage the audience. Although the presentation contains the technical, clinical jargon that is used within the medical field, it provides the audience with tools to help them navigate this world. Including videos of how to read a journal article and discussing what evidenced based practice, an audience member is provided with knowledge to control their own journey. The videos embedded within the presentation can be accessed and reviewed as needed. This presentation is valuable in that it is not static. As a consultant and someone who presents on the topic regularly, this is an invaluable resource. It makes me wonder why I hadn't thought of doing this before...
- I think your point about telling a story is good. Telling stories is a powerful approach to everyone and enhances learning and memory. The Prezi is excellent. The video of Temple Grandin provides a great deal of insight into the world of a person with autism. She speaks in way that I think she would like to be spoken to. Concrete language. A good way to start the presentation. I am not sure about the ABA vs IBI section. There is no other information there. The Rosie video is very absorbing since she is very articulate. It illustrates a variety of challenges but that the family can cope which is encouraging. Her meeting with Tony is good for briefly covering bullying and alienation. Her expression of

appreciation for Tony's help and advice really illustrates her dad's point that she has great social skills. She has a lot of empathy too. With the inclusion of the Autism Niagara video and your audio you provided local, professional and personal perspectives. I found the NAC video in comparison to be dry and a bit boring. You have managed to include all possible perspective through the videos and this greatly enhance the text. Thanks.

Revision Criteria

I took into consideration my evaluators feedback and made the following revisions to the workshop:

- I added material to my slide on Applied Behaviour Analysis with examples provided for the audience.
- I ensured that terminology used throughout the presentation can be discussed and simplified. I found it important to use the terms family may hear from professionals, but during the presentation one of the benefits of face-to-face is the opportunity to provide clarification and further definitions of terms used.
- Although some of the videos may come across as boring, I felt strongly that parents become familiar with Evidence Based Practice (EBP) and what is available online, therefore, I kept the content in my project.

The following are the outcomes from my project:

1. Workshop: Navigating Evidence-Based Practice for Families of Children with ASD
 - Visual Supports Resource List
 - Website Resource List
 - Local Resource List
2. A Brief Facilitator's Guide

Navigating Evidence-Based Practice

For Families and Caregivers of Children with ASD

Prezi ULR:

http://prezi.com/9voum-ikhoew/?utm_campaign=share&utm_medium=copy

Facilitator's Notes

Facilitator's Background

This workshop has been designed for an audience of families and/or caregivers of children with an Autism Spectrum Disorder (ASD), to assist in developing a better awareness of evidence-based practice (EBP). It is a vehicle to provide resources, to help families navigate complicated systems, and to give them the support and understanding of the challenges they face. The workshop presenters/facilitators should have the following knowledge:

- Excellent understanding of Autism Spectrum Disorders.
- Excellent understanding of Evidence-Based Practice (EBP) and the relationship between ASD and EBP. Including the four chosen strategies:
 1. Applied Behavioural Analysis (ABA)
 2. Visual Supports
 3. Structured Learning Environments (SLE)
 4. Social Scripts
- Understanding of local resources and supports that are available for families and/or caregivers.
- Ability to clarify and simplify terminology.

Presenting with Prezi

According to Reichow et al. (2011) the World Wide Web is the most popular method of obtaining information for families of children with ASD. Prezi was chosen as an ideal platform in light of this research, as well as because:

- It is a free, on-line, portable cloud-based presentation software.
- It is accessible to both families and facilitators.
- It enables the presentation of information through a story (instead of the traditional method of using a PowerPoint).

The following template includes screenshots of the presentation, with Facilitator Notes included. Please refer to the notes to help you navigate this Prezi. This is intended to be a flexible resource so that you can tailor it to meet individual families' needs and includes your own personal and professional experiences. This resource has been created for the Hamilton-Wentworth Community, Ontario.

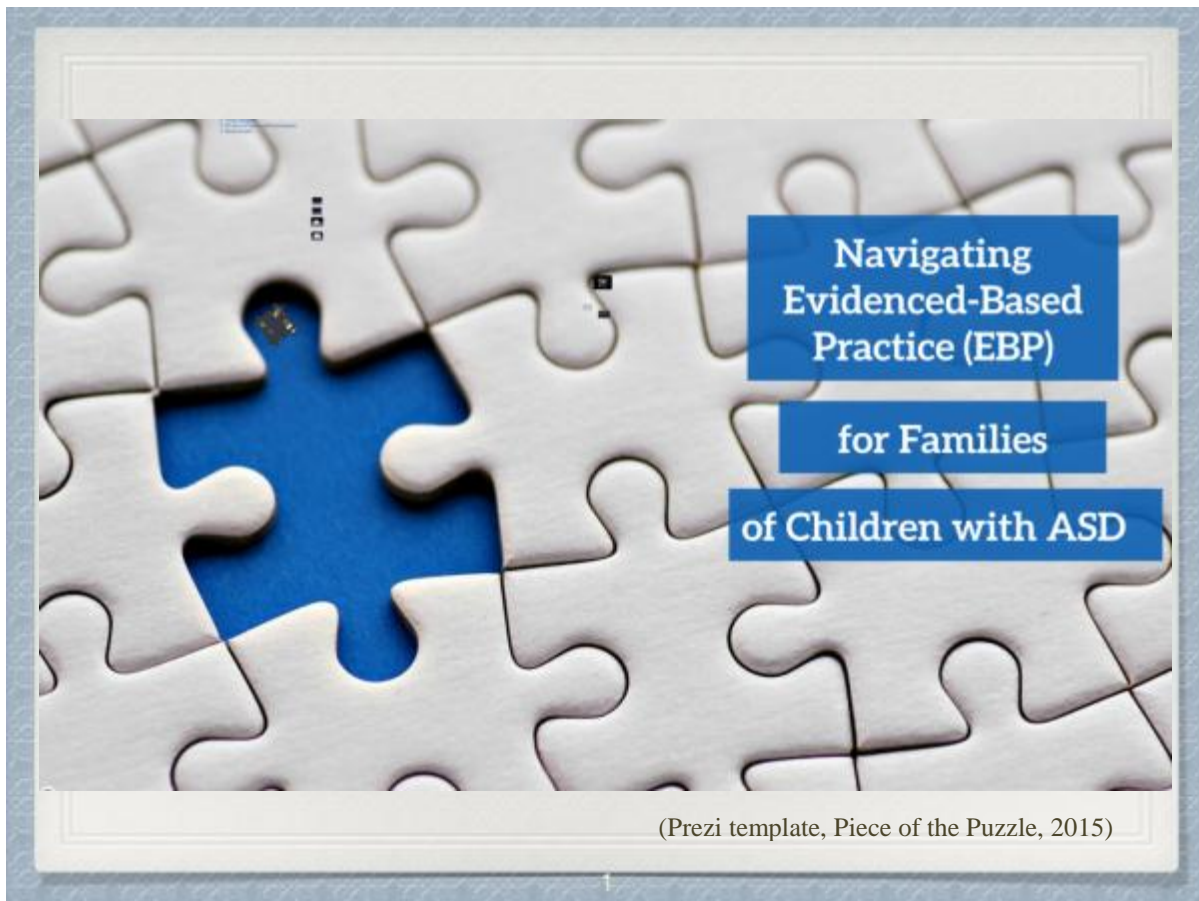


Image 1

1. The intention of this workshop is to enhance awareness of and the importance of evidence-based practice (EBP) for children diagnosed with an Autism Spectrum Disorder (ASD).
2. To assist families and caregivers in making informed decisions about treatments that will have a positive impact on their child's characteristics and enhance personal growth.
3. To provide information on local resources and assisting families to navigate EBP.

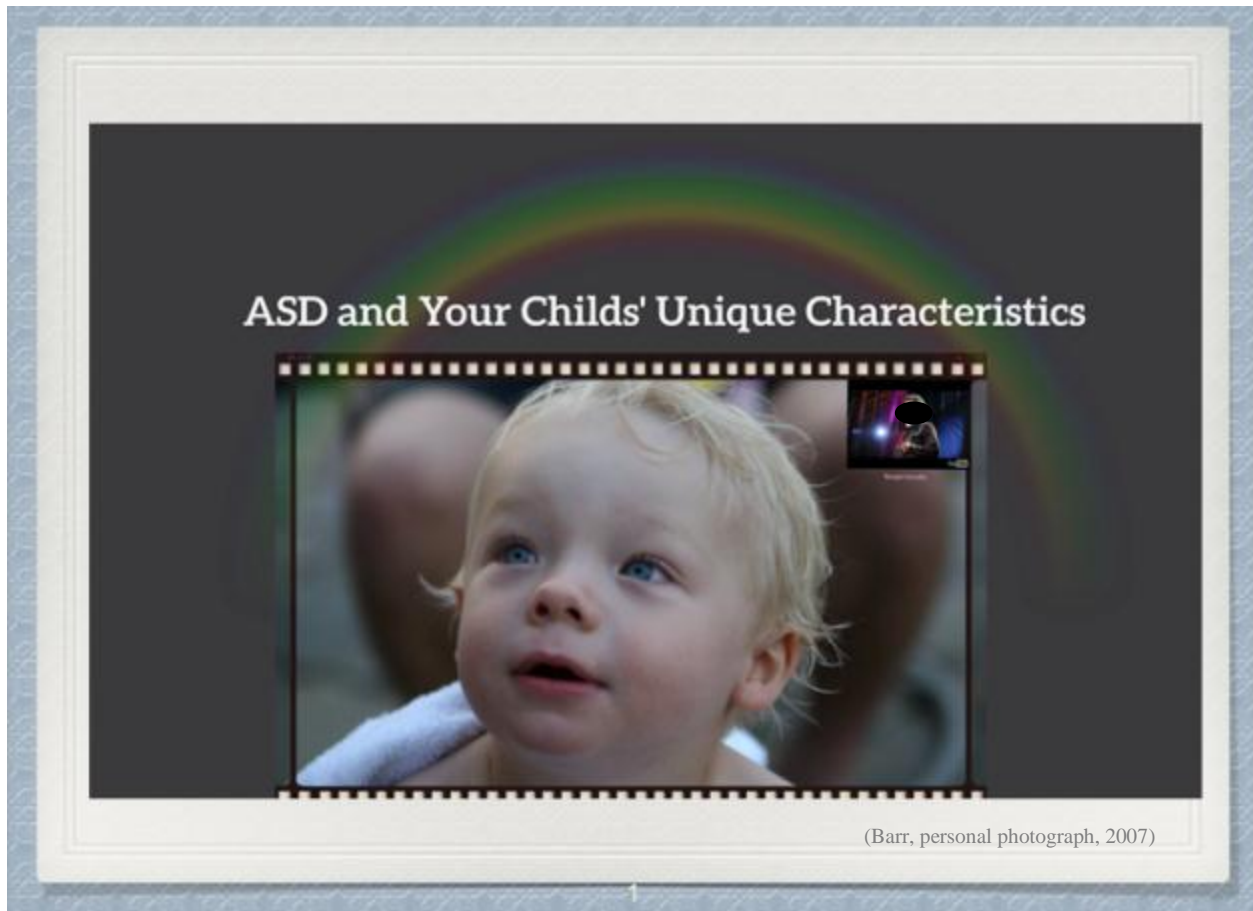
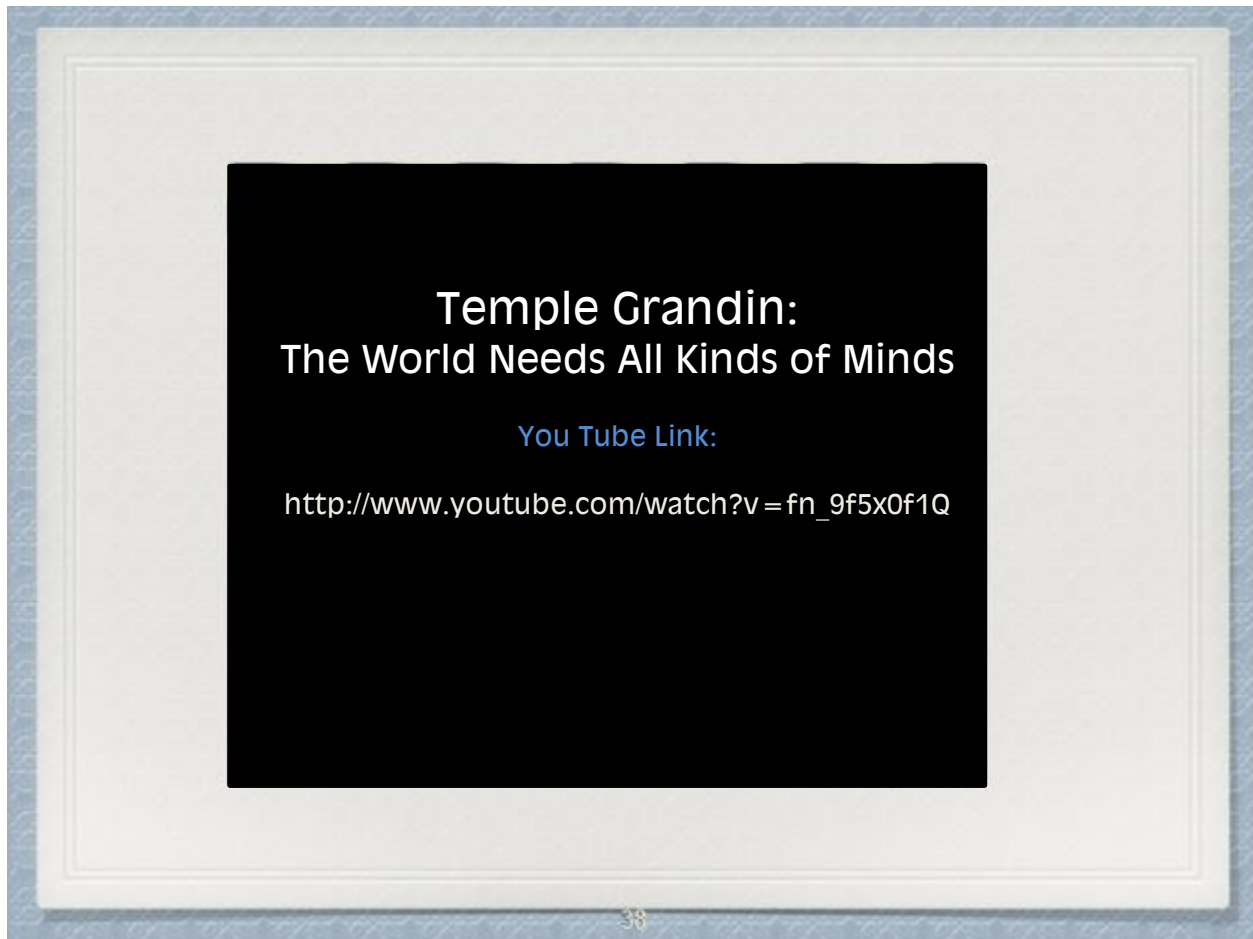


Image 2

- Prevalence rates for children with an ASD have increased dramatically in North America to the current estimation of 1 in 68 (CDC, 2014).
- ASD is a lifelong, multifaceted neuro-developmental disorder (Szatmari, 2010).
- The overall severity and symptoms of ASD can differ markedly from one person to another and are very unique (American Psychological Association, 2013)
- The ratio of boys to girls diagnosed with an ASD is 4:1.
- Review genetics and environmental factors.

Audience Questions:

- What unique characteristics do you see in your own children?

**Image 3**

Play Temple Grandin Video: The World Needs All Kinds of Minds

You Tube Link: http://www.youtube.com/watch?v=fn_9f5x0f1Q

Audience Questions

- What are your thoughts on this video?
- Are any of your children visual learners, like Temple?
- What do you think Temple's main point or what is the one thing you want to remember from this video?

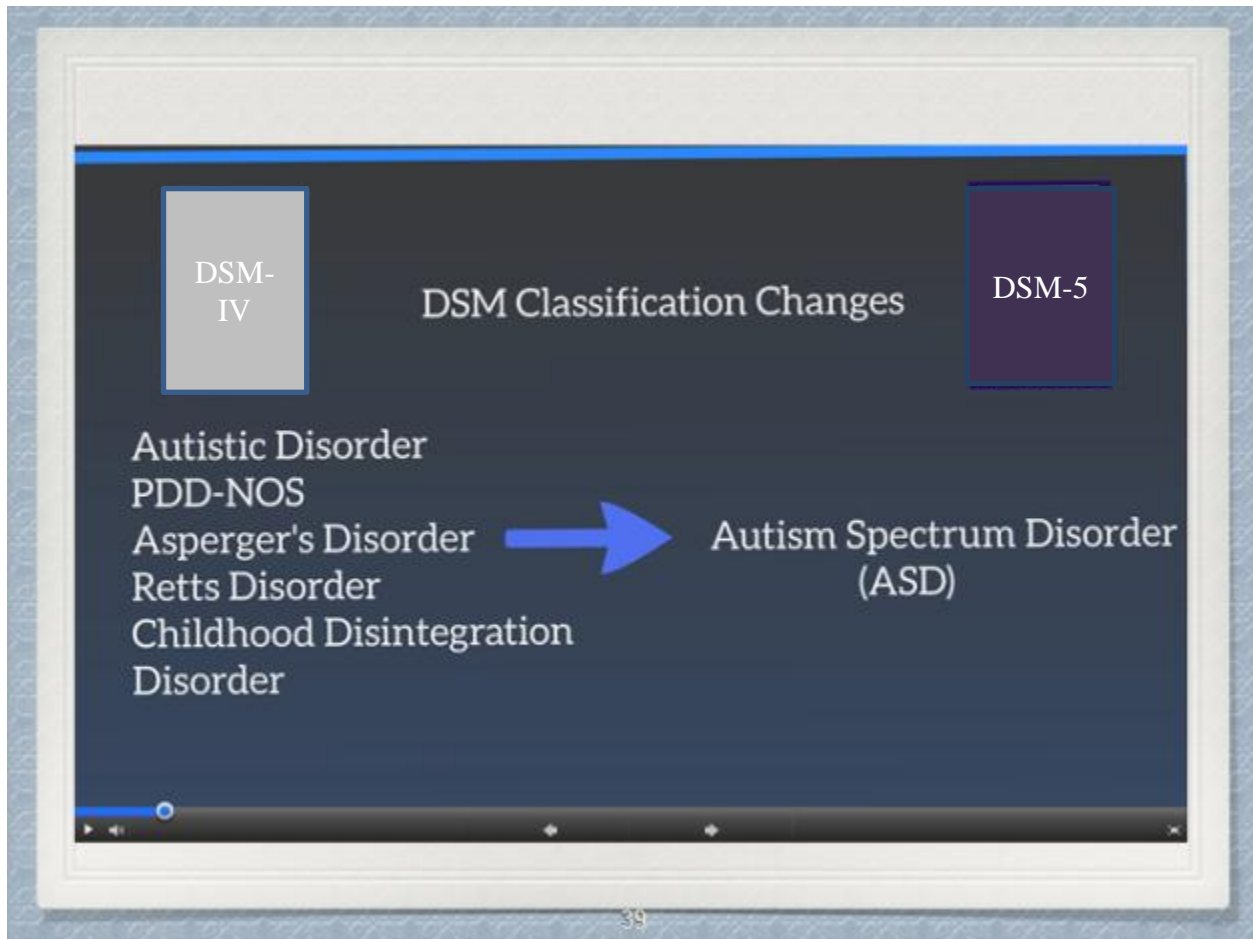


Image 4

- DSM-IV-TR edition published by the American Psychiatric Association (2000) was replaced by the DSM-5 in April 2013.
- It is believed that these changes “will lead to more accurate diagnosis and will assist physicians and therapists to design better treatment interventions for children from ASD” (APA, 2013, Dr. Scully).



Image 5

- According American Psychological Association (2013), a child diagnosed with an ASD must have deficits in both social communication and social interaction. It is noted that the deficits cannot be attributed to a general development delay. There are also deficits in restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least two of the four symptoms.

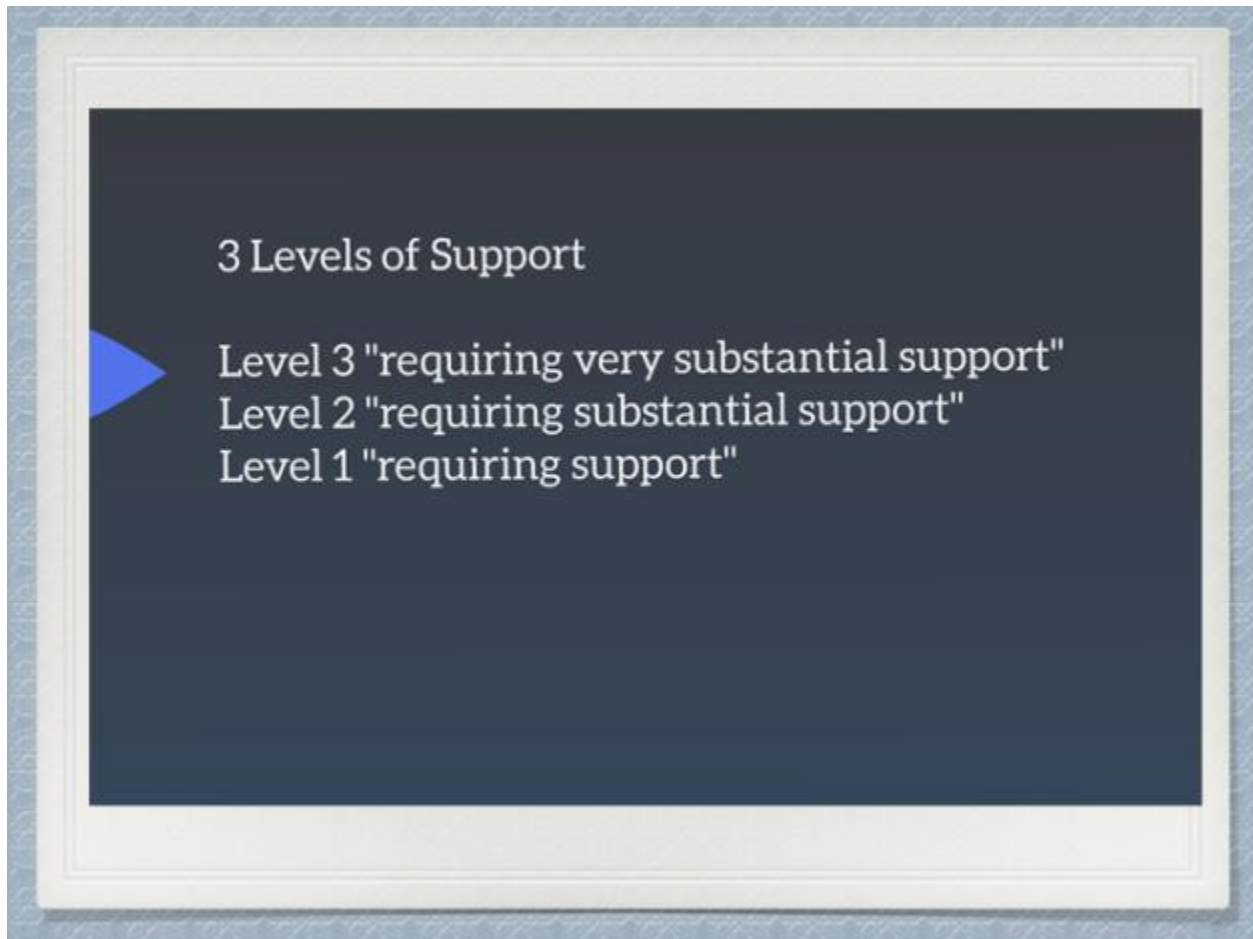


Image 6

According to the American Psychological Association (2013):

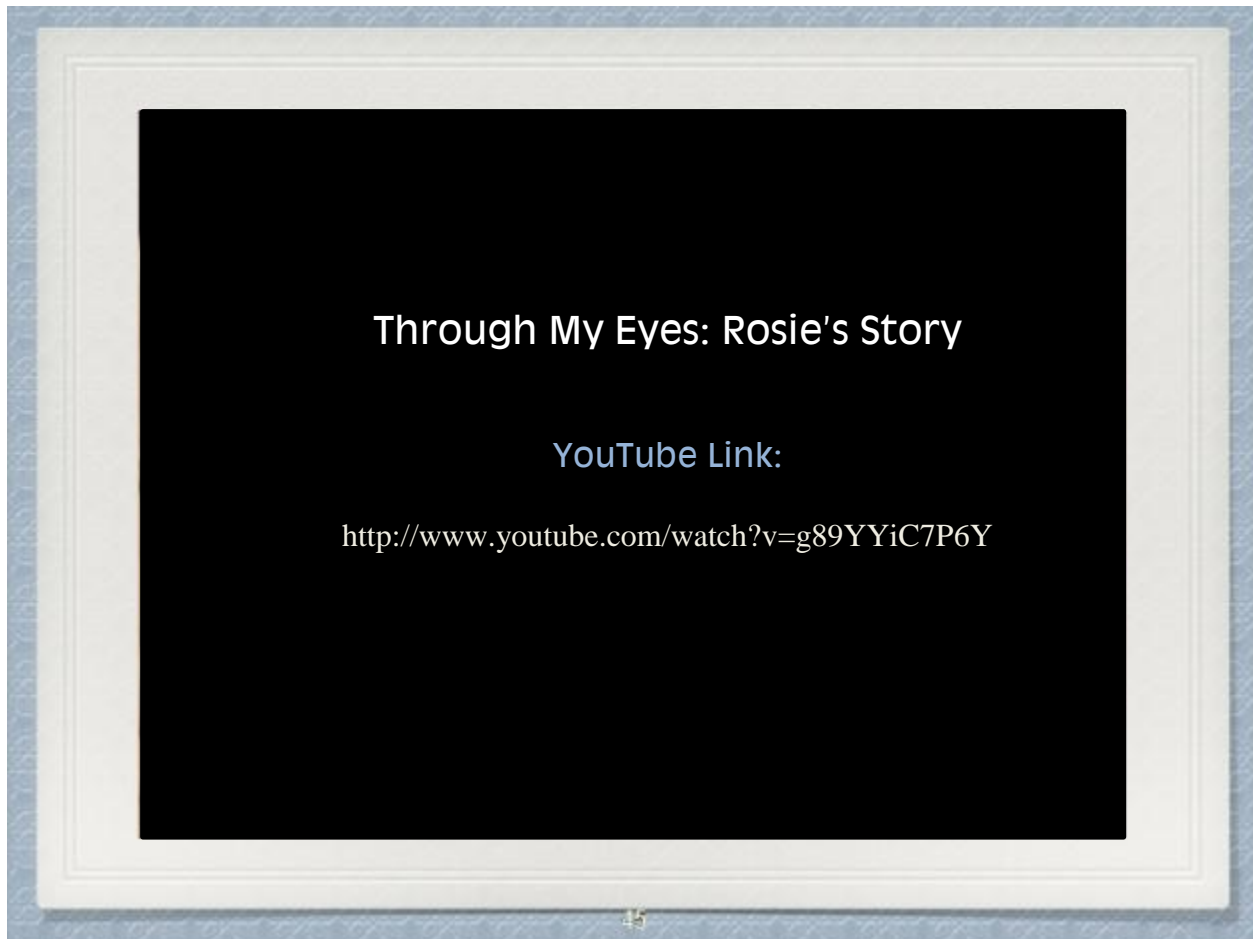
- ASD must be present in early childhood (but may not become fully displayed until social demands exceed limited abilities).
- The symptoms presented in ASD must limit and impair an individual's daily life.
- Review 3 Levels of Support.



Image 7

According to the American Psychological Association (2013), a child diagnosed with ASD must have deficits in both social communication and social interaction. Children must have deficits in the following three areas:

1. Social/emotional reciprocity
2. Non-verbal communication behaviour used for social interaction
3. Developing, understanding and maintaining relationships

**Image 8**

Through My Eyes: Rosie's Story

Video Link: <http://www.youtube.com/watch?v=g89YYiC7P6Y>

Questions for Audience:

- What are the social communication and interaction strengths, families/ caregivers observe in their children after watching the video?
- What are the social communication and interaction challenges that families/ caregivers see in their children after watching the video?
- Additional thoughts and questions?



Image 9

According to the American Psychological Association (as cited by Centers for Disease Control and Prevention, 2015), a child diagnosed with ASD may have deficits in restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least two of the following four symptoms:

1. Stereotyped or repetitive speech, motor movement or use of objects.
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour or excessive resistance to change.
3. Highly restricted, fixated interests that are abnormal in intensity or focus.
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

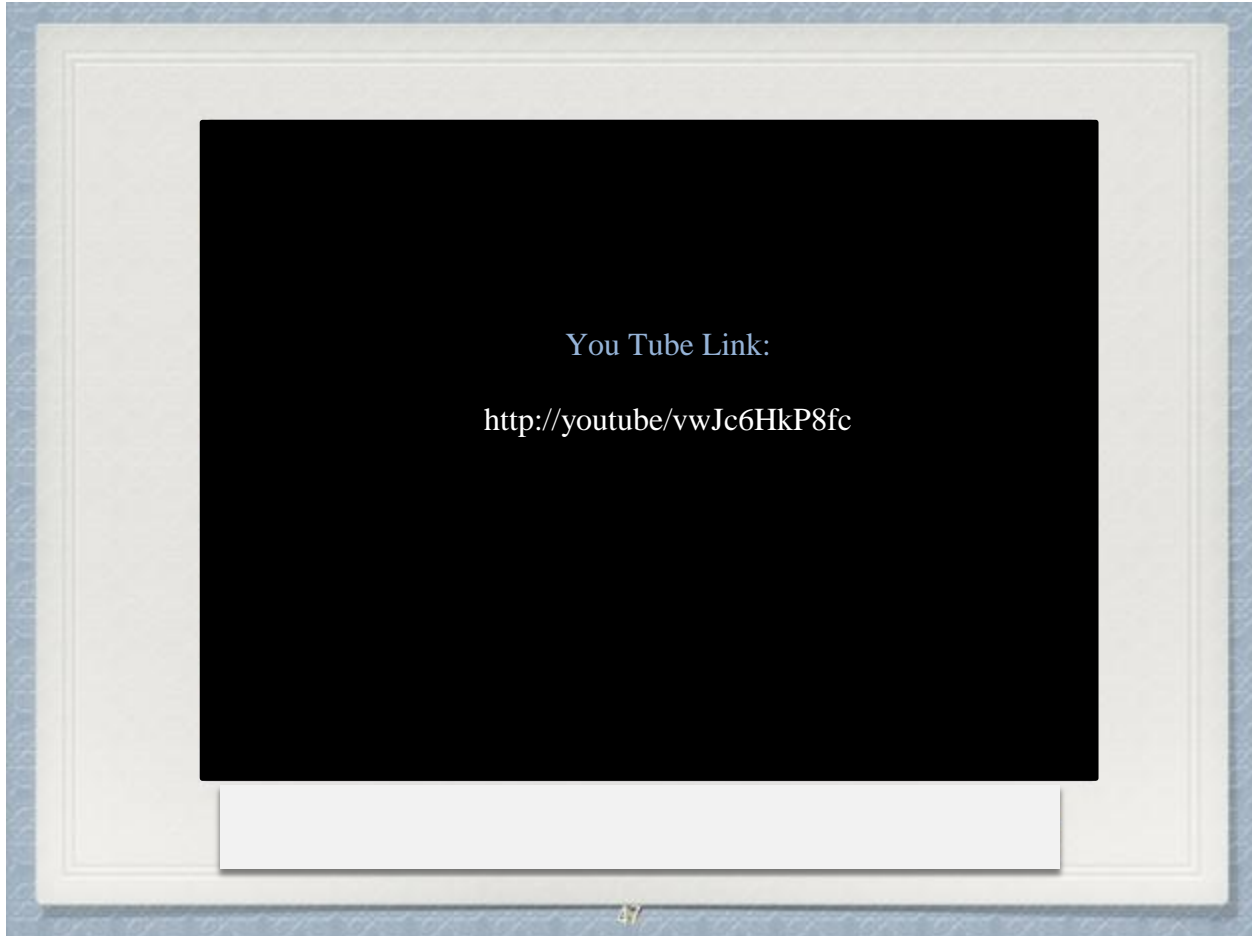


Image 10

You Tube: <http://youtube/vwJc6HkP8fc> (this video cannot be embedded and is not hyperlinked)

According to DSM-5, 2013:

- Additional Criteria must be present in the early developmental period in order to be diagnosed with ASD.

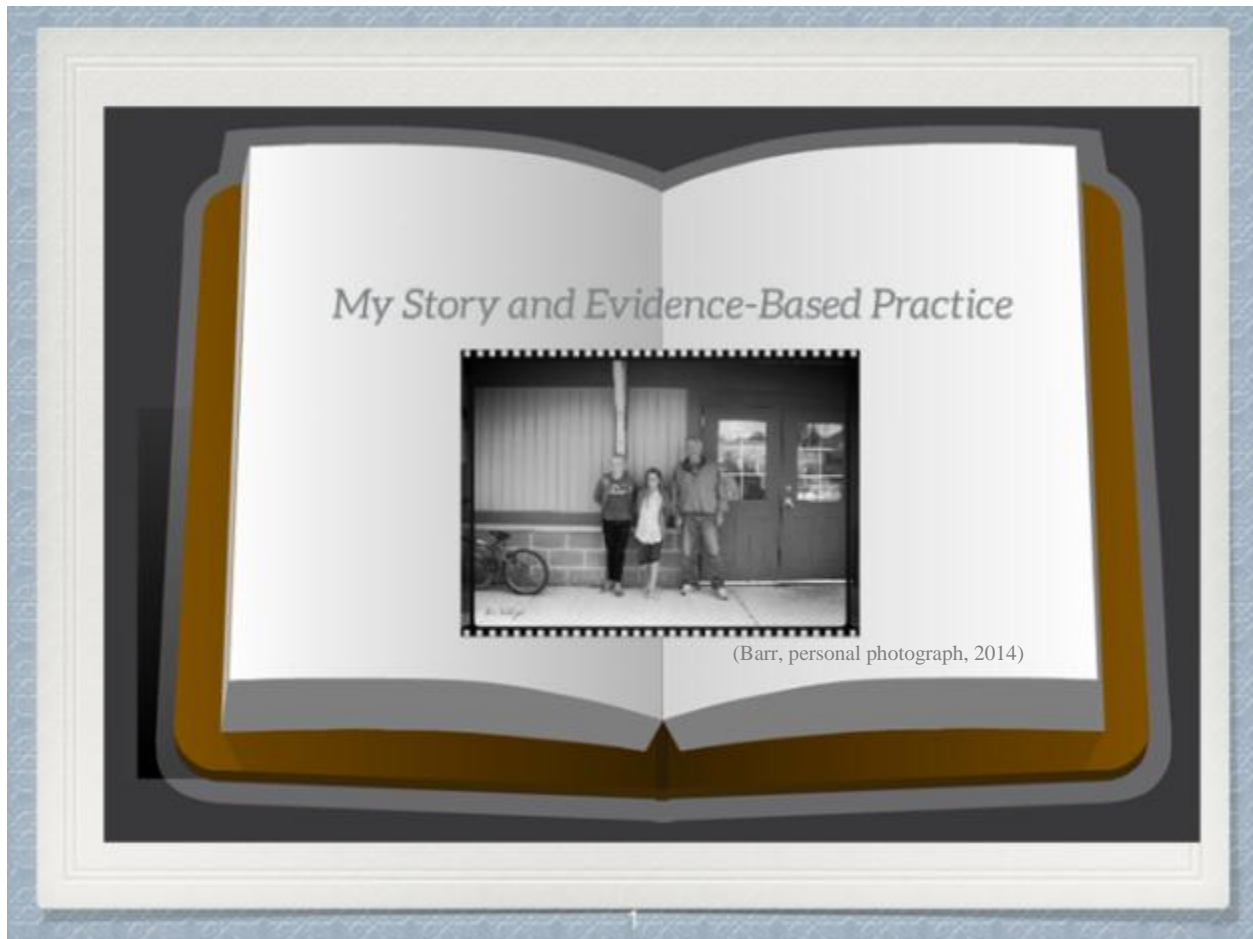


Image 11

- Please add in your own story if it is relevant.

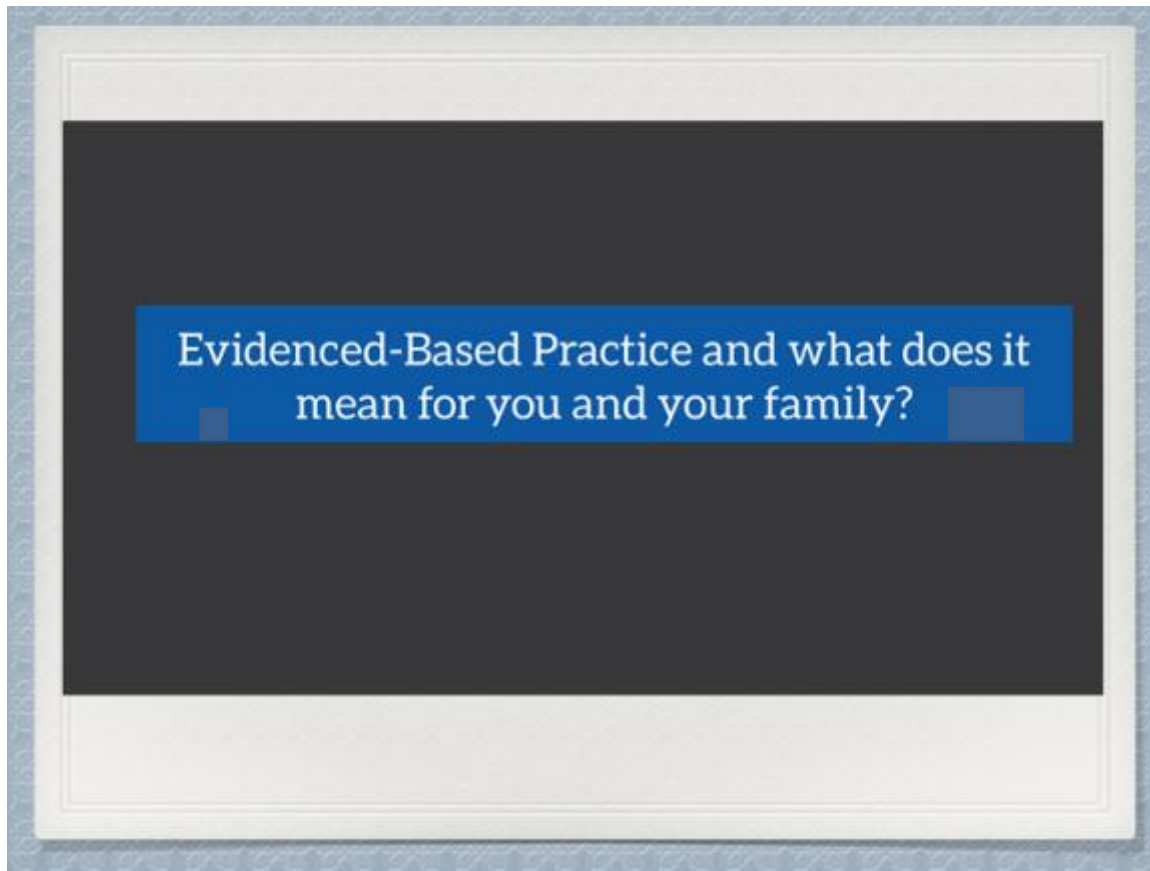


Image 12

Recently, we have seen an increase in the number of children being diagnosed with an ASD. Families are being presented with a multitude of new treatments.

Some treatments claim to be the cure, while others charge families thousands of dollars with the promise of improvement in outcomes for their children. Without sound research, some treatments are potentially harmful to children.

Today we will discuss:

- How to review information based on research.
- Define evidence-based practice (EBP).
- How families/ caregivers can make informed decisions around best treatments for their children.

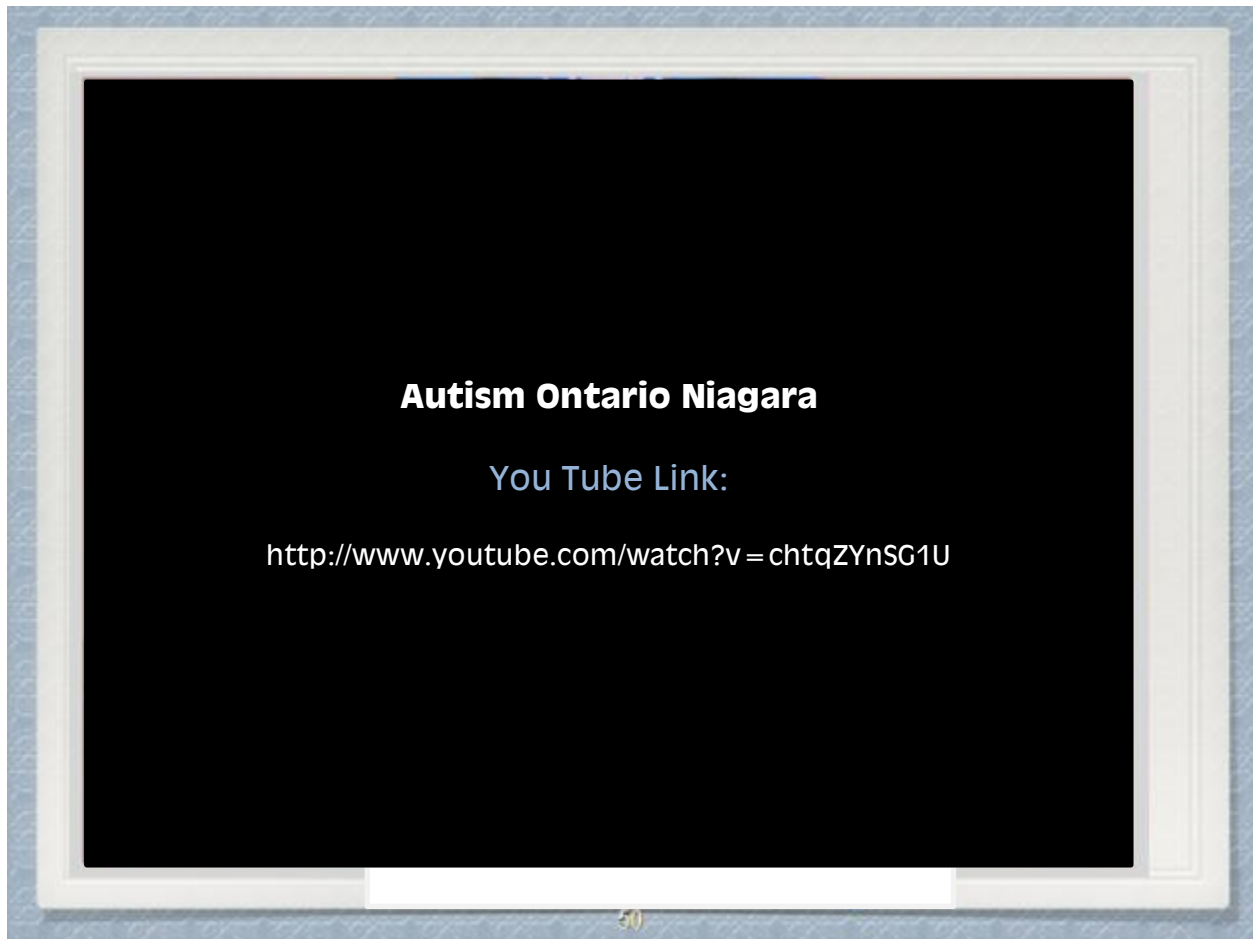


Image 13

This video was created for Autism Awareness day by AO Niagara.

You Tube Link: <http://www.youtube.com/watch?v=chtqZYnSG1U>

Questions for the Audience:

- What do you find most difficult about choosing treatments?
- Where do you go for help?

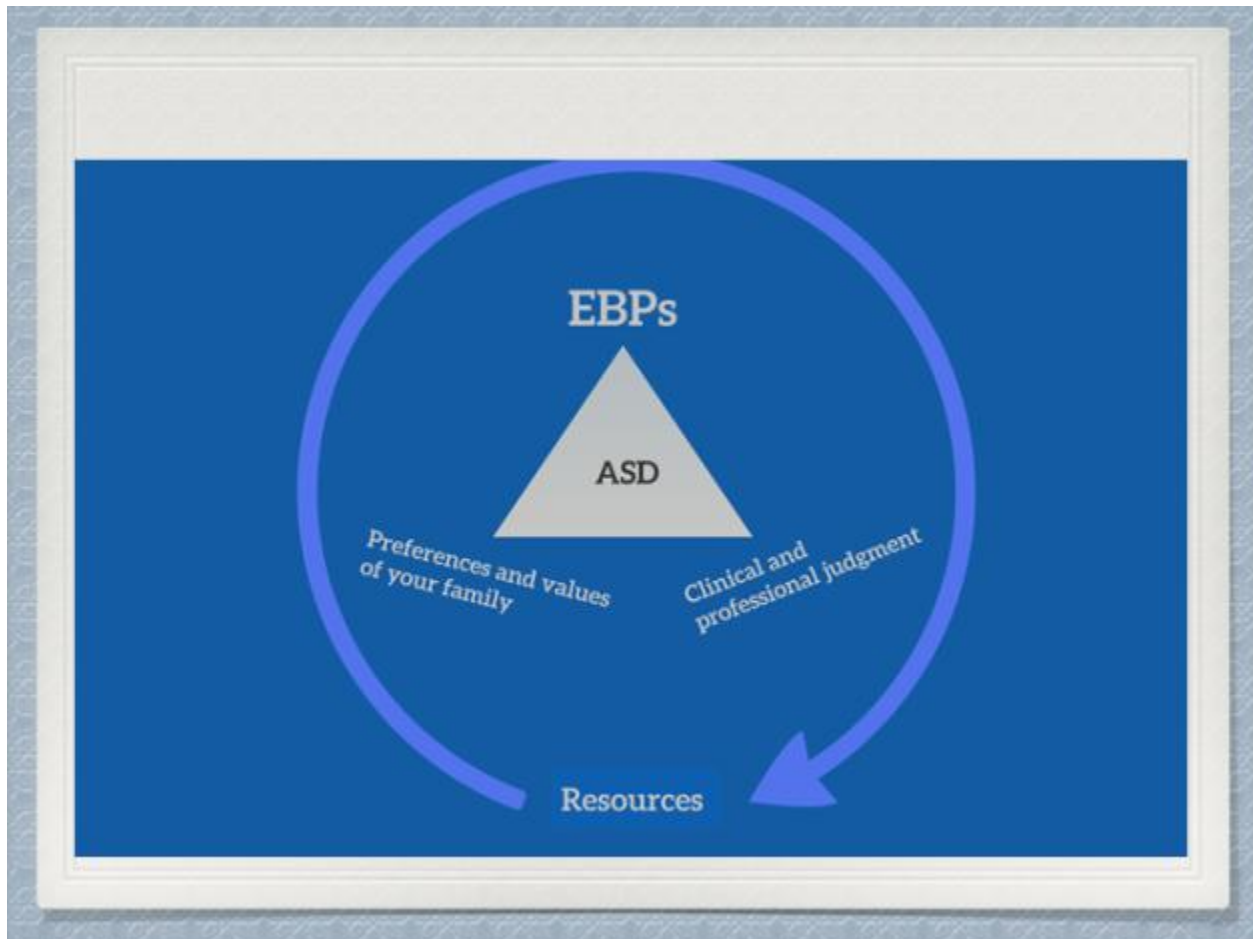


Image 14

Please discuss, while taking into consideration the following for families:

- Stress and dynamics
- Time Commitment and financial requirements needed for treatment
- Cultural and religious values
- Supports available (both formal and natural)

Questions

- Can you bring in an article / example of recommendations that will not work for your family?
- What do parents want professionals to take into consideration when considering EBP?

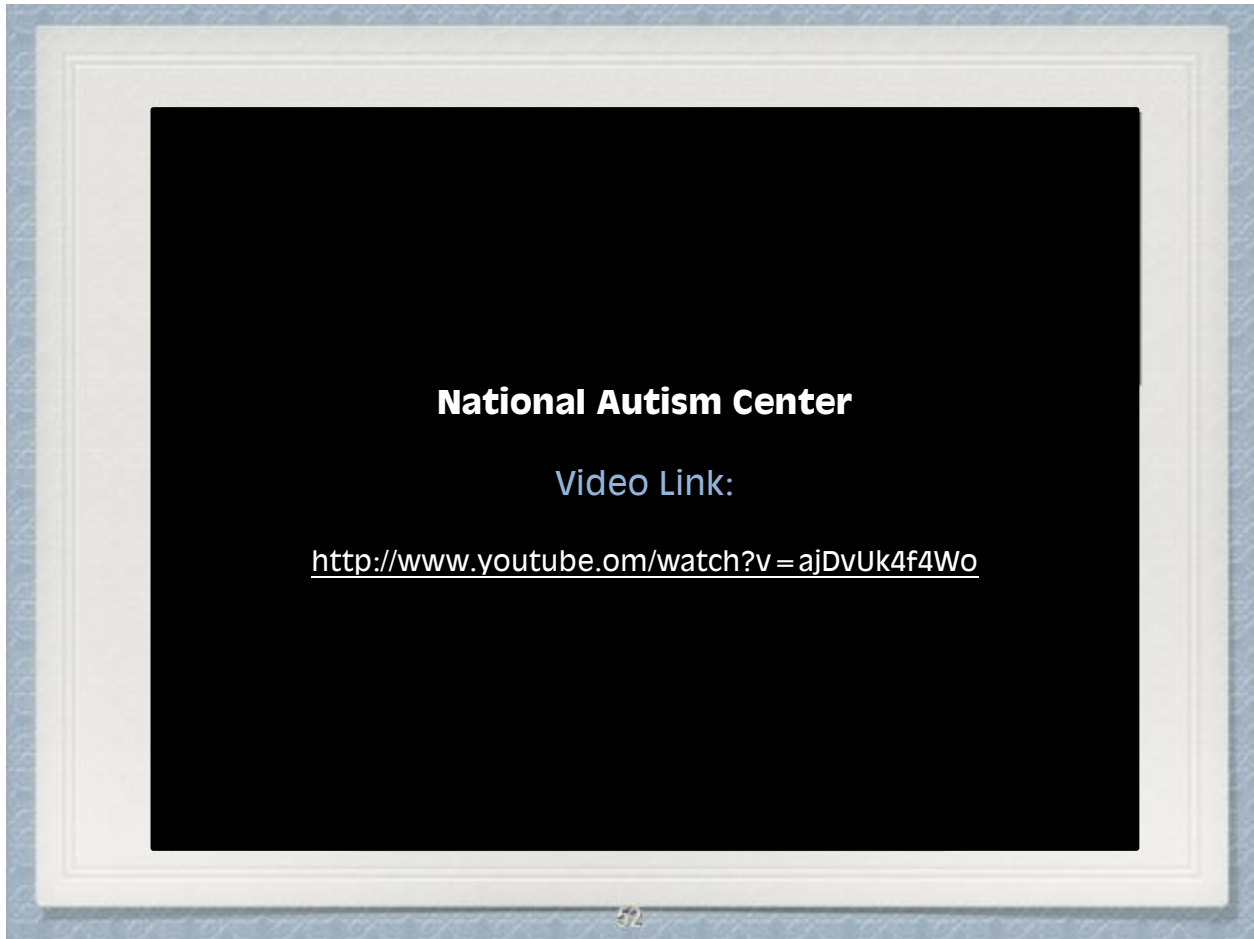


Image 15

The National Standards Project, Phase 2 (National Autism Center, 2015) has available free resources for families, professionals and individuals with ASD and EBP.

Website: <http://www.nationalautismcenter.org/>

You Tube Link: <http://www.youtube.com/watch?v=ajDvUk4f4Wo>

The facilitator may prefer to have a downloaded copy for parents to review and reference.

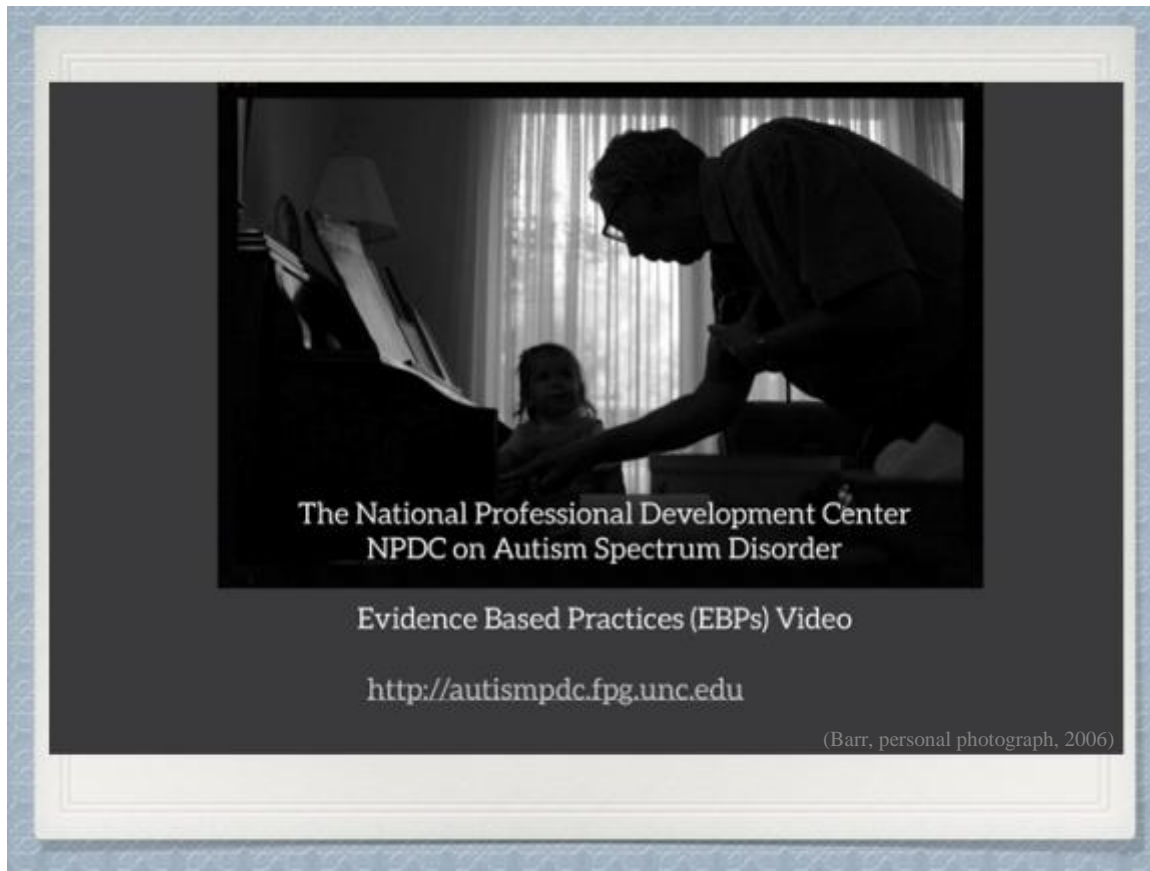


Image 16

Please click on the link for the video created by NPDC on EBPs.

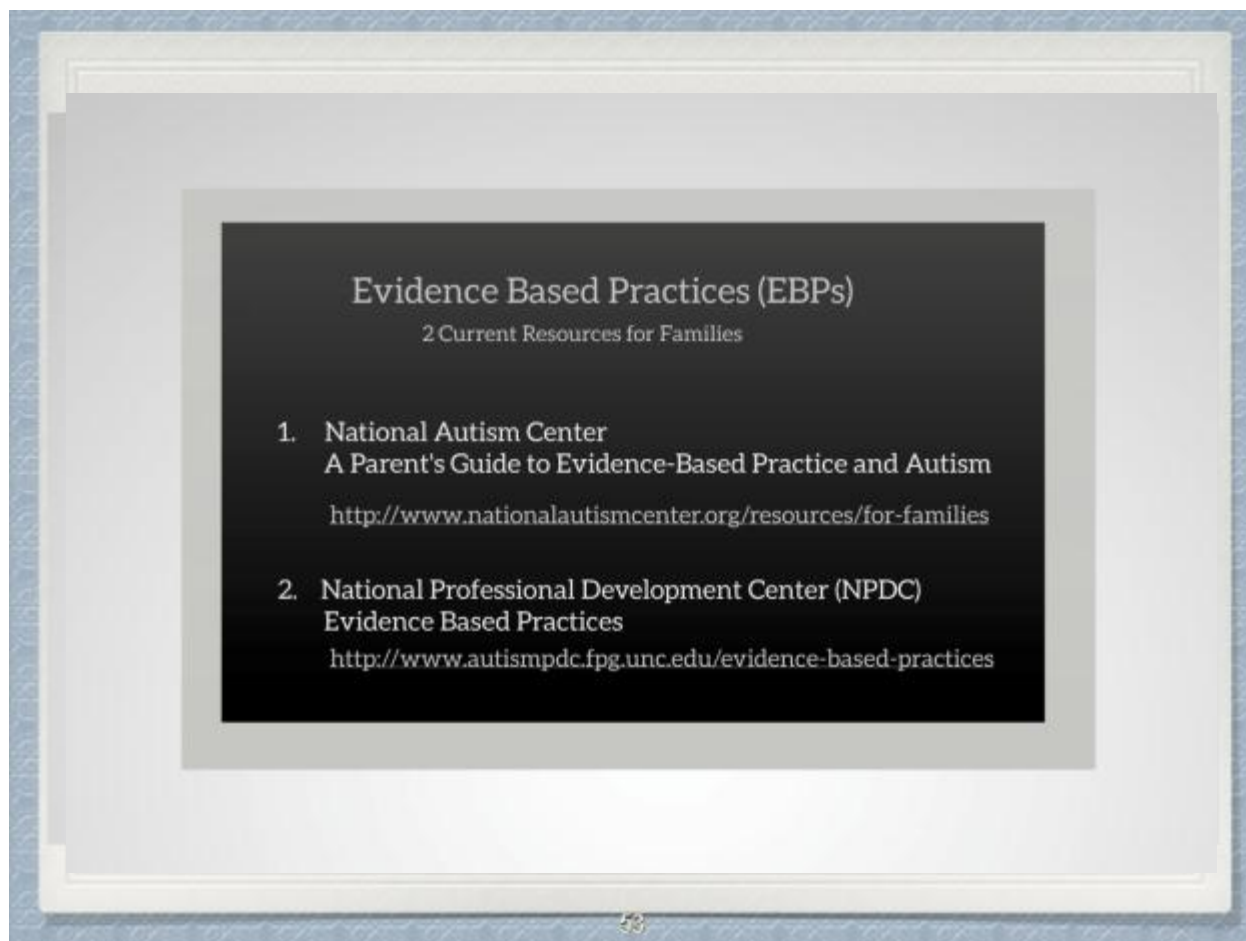


Image 17

The above resources are hyperlinked to the most current and EBP for families of children with ASD.

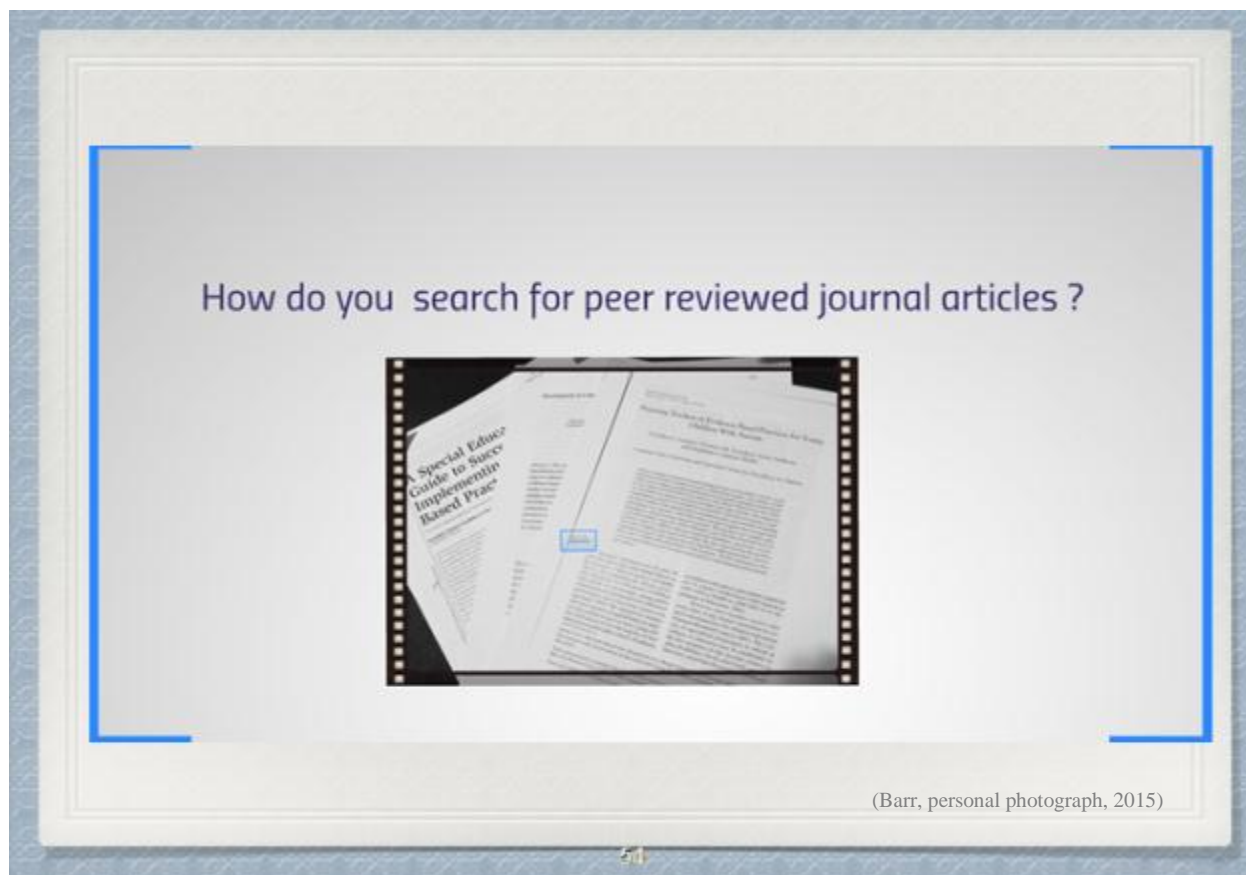


Image 18

Reichow et al., (2011) surmise that the World Wide Web is primarily used by families to search for information. However, there are no guidelines on how to navigate the web. It is important to note that the quality of on-line resources is not always accurate and to have some recommended websites for further review.

Questions for the Audience:

- How do you search for information on the Internet?
- Do you ever search for journal articles? What is a peer reviewed journal article?
- If you do search for journal articles how do you perform a search?
- Are all articles written of equal quality and evidence-based? Bring in a sample article to share (e.g., hyperbaric chamber or chelation therapy).

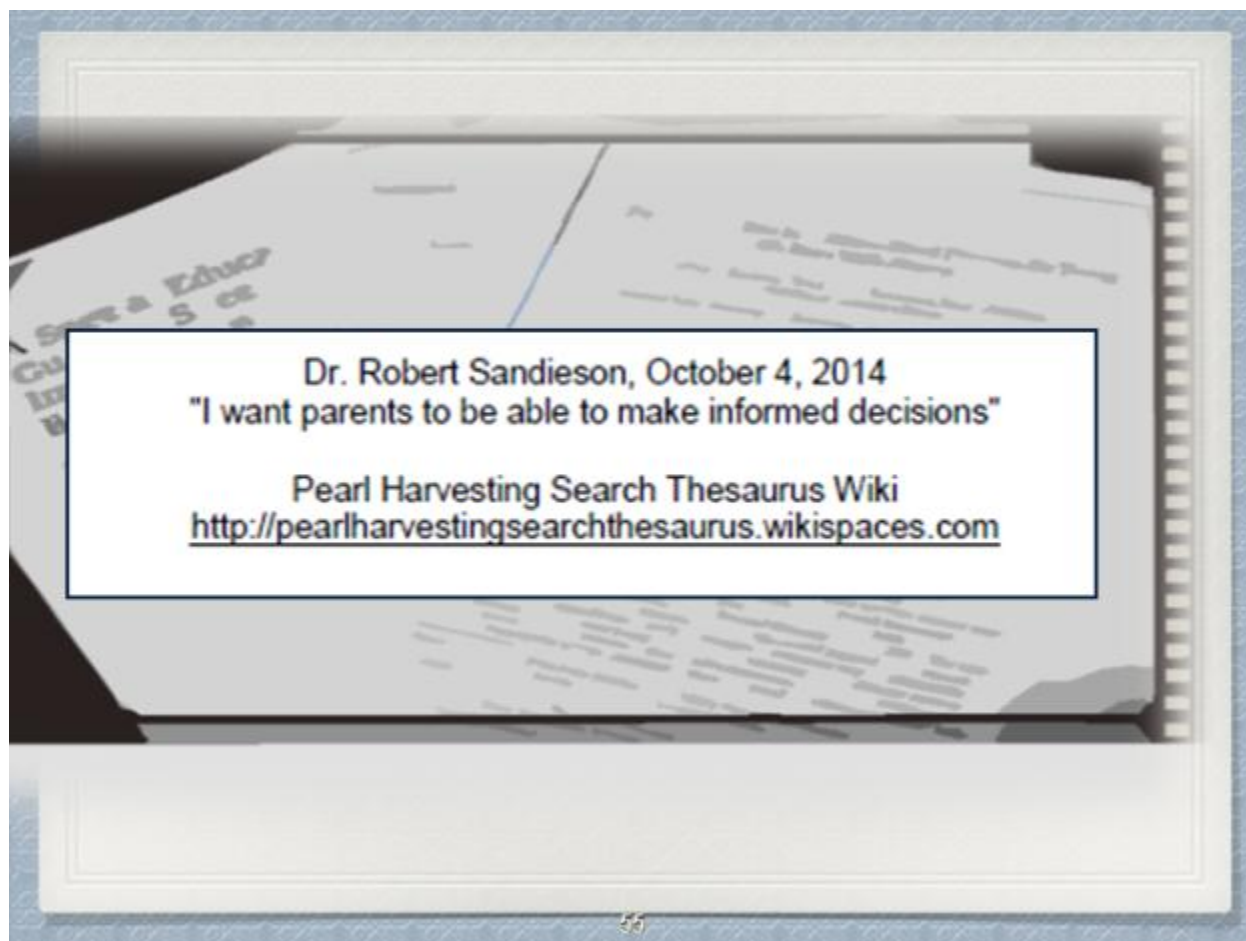


Image 19

Pearl Harvesting Search Thesaurus Wiki is hyperlinked.

Please demonstrate for families how to use this resource online.

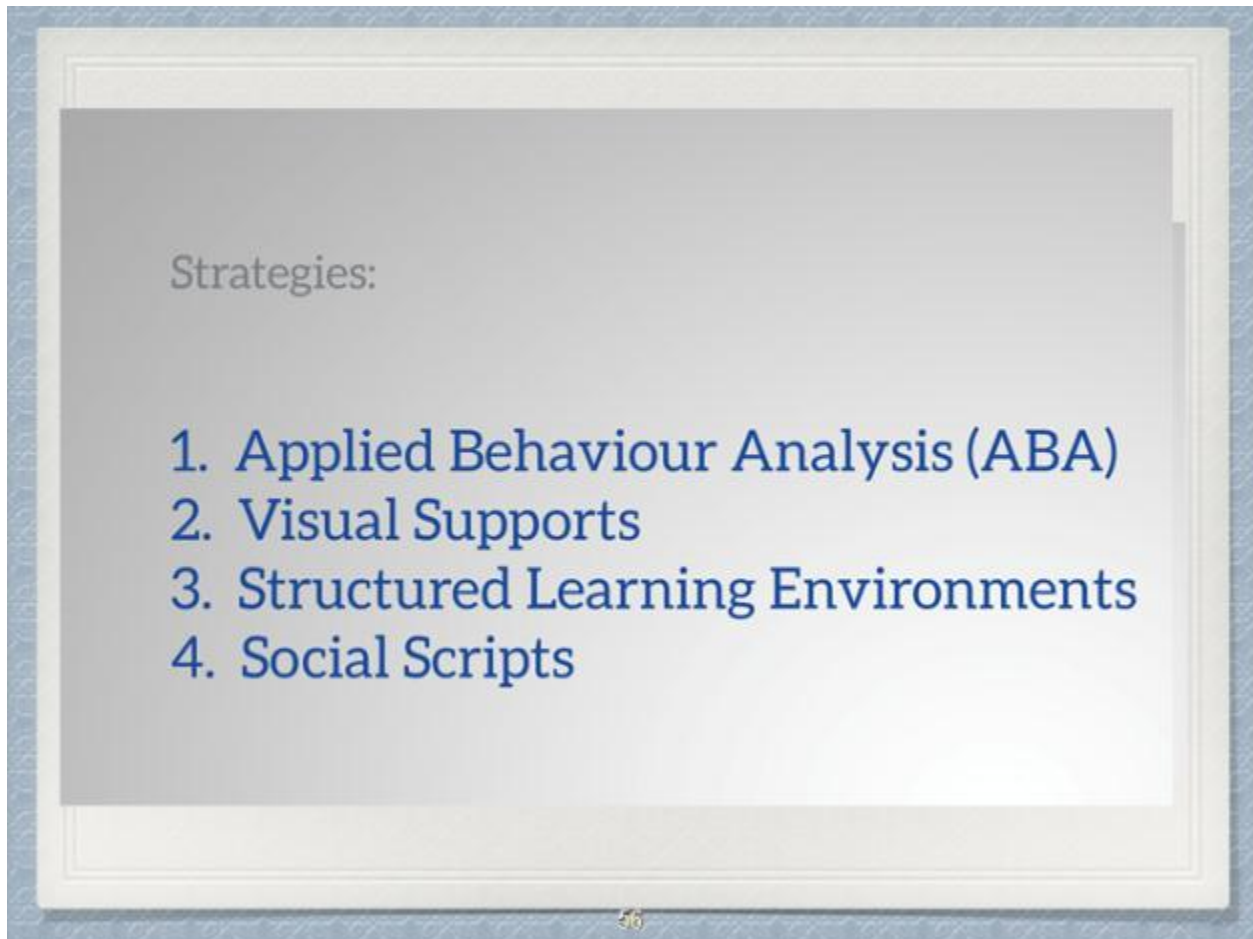


Image 20

According to National Standards Report (2010):

- Applied Behavioural Analysis (ABA)- established treatment
- Visual Supports – established treatment
- Structured Learning Environment - emerging treatments that cannot be overlooked
- Social Scripts - emerging treatments that cannot be overlooked

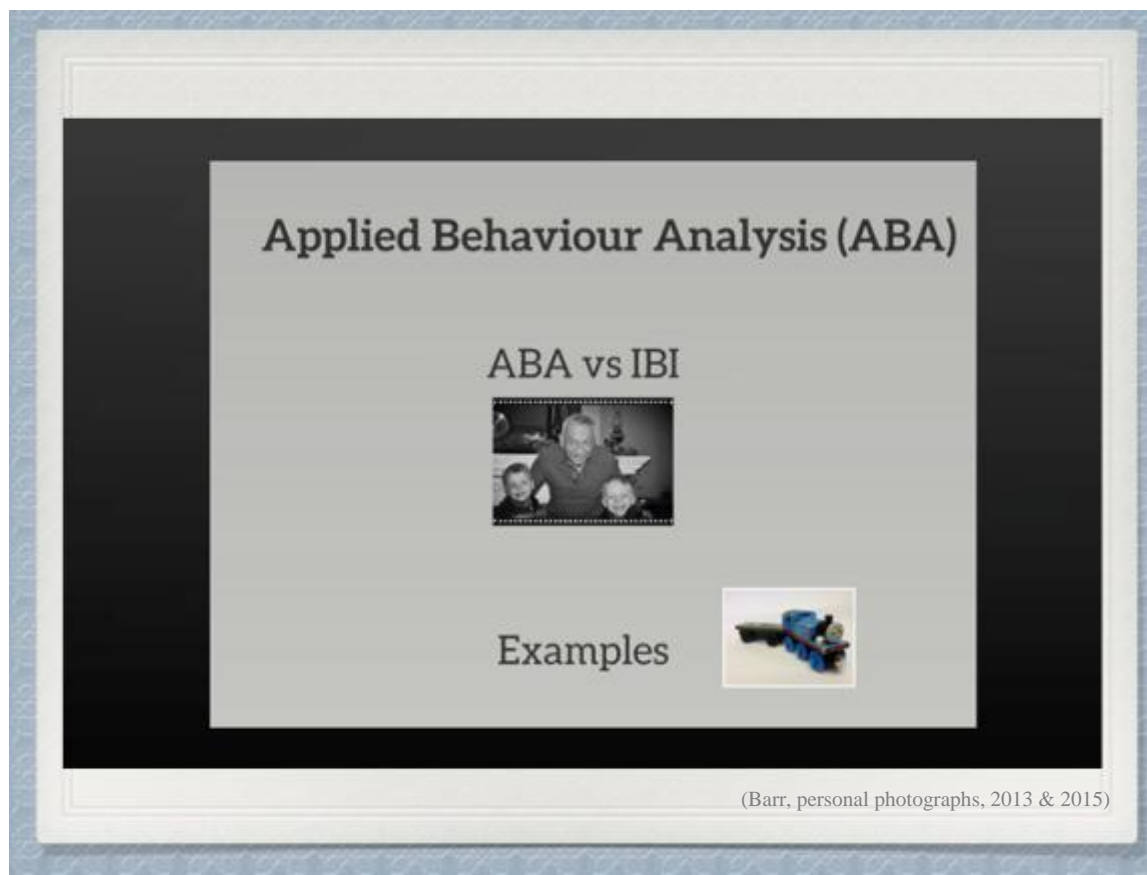


Image 21

- ABA is the most common effective treatment for ASD (Matson et al., 2014).
- ABA is a scientific approach to understanding behaviour and how the behaviour is affected by the environment.
- It can be used across multiple environments (e.g., home, healthcare, school).
- Research has demonstrated that ABA can help to decrease challenging behaviours, increase positive behaviours, provide structure, build on skills and even increase motivation for children with ASD (Hundert, 2010).

Clarify the differences between ABA vs Intensive Behavioural Intervention (IBI).

- IBI is based on the principles of ABA. Therapy is provided 1:1 or in a small group setting, by trained interventionists and is overseen by a Psychologist.
- Children will receive a minimum of 20 hours of therapy per week.

Questions for the audience

- Describe the differences are between ABA and IBI?

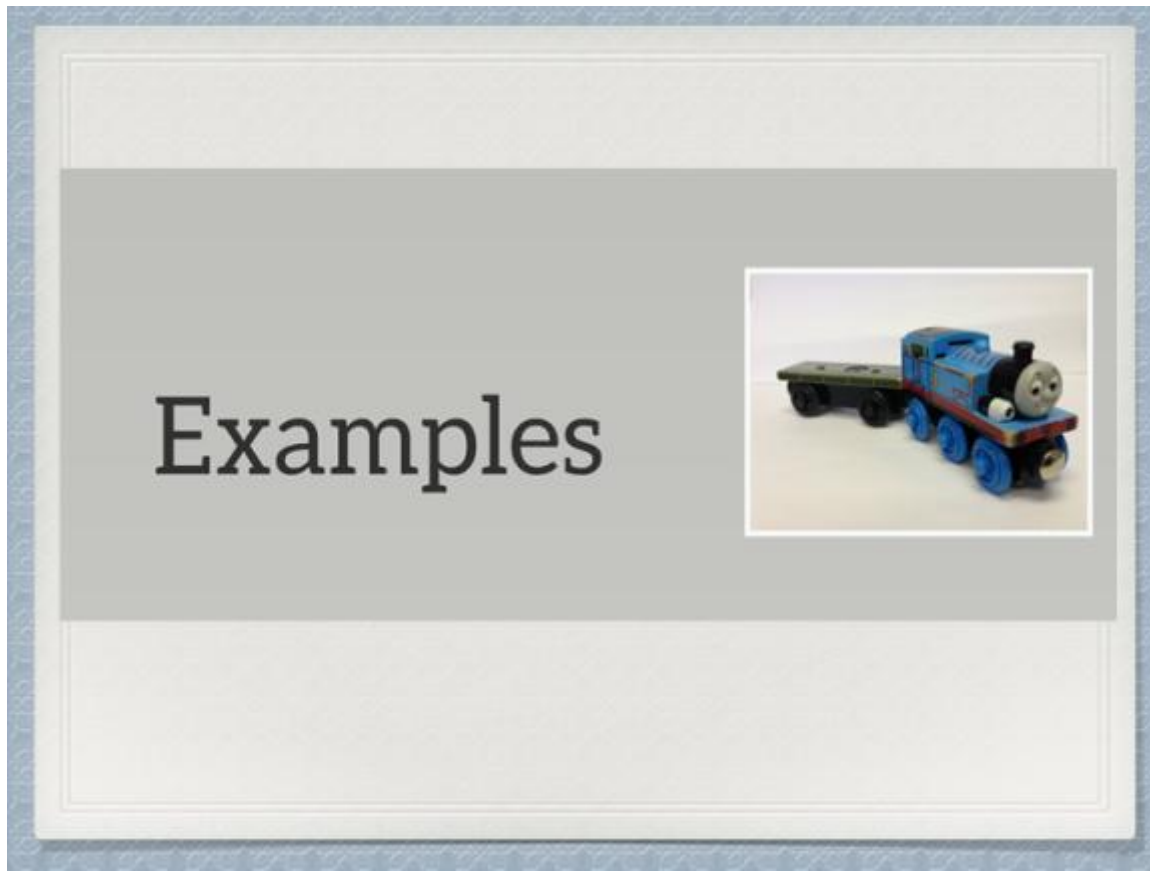


Image 22

Discuss examples relevant to home programming (shaping, modeling, reinforcement).

Questions for the Audience to help provide exposure to new terminology:

- What types of reinforcers (i.e., rewards) do you use at home? How is it different for children with ASD?
- What are the steps you use to teach your child new skills (e.g. Task Analysis)?
- How much assistance do you provide to your child (e.g., prompting, modeling, chaining or shaping)?
- How do you reduce assistance (e.g., fading)?

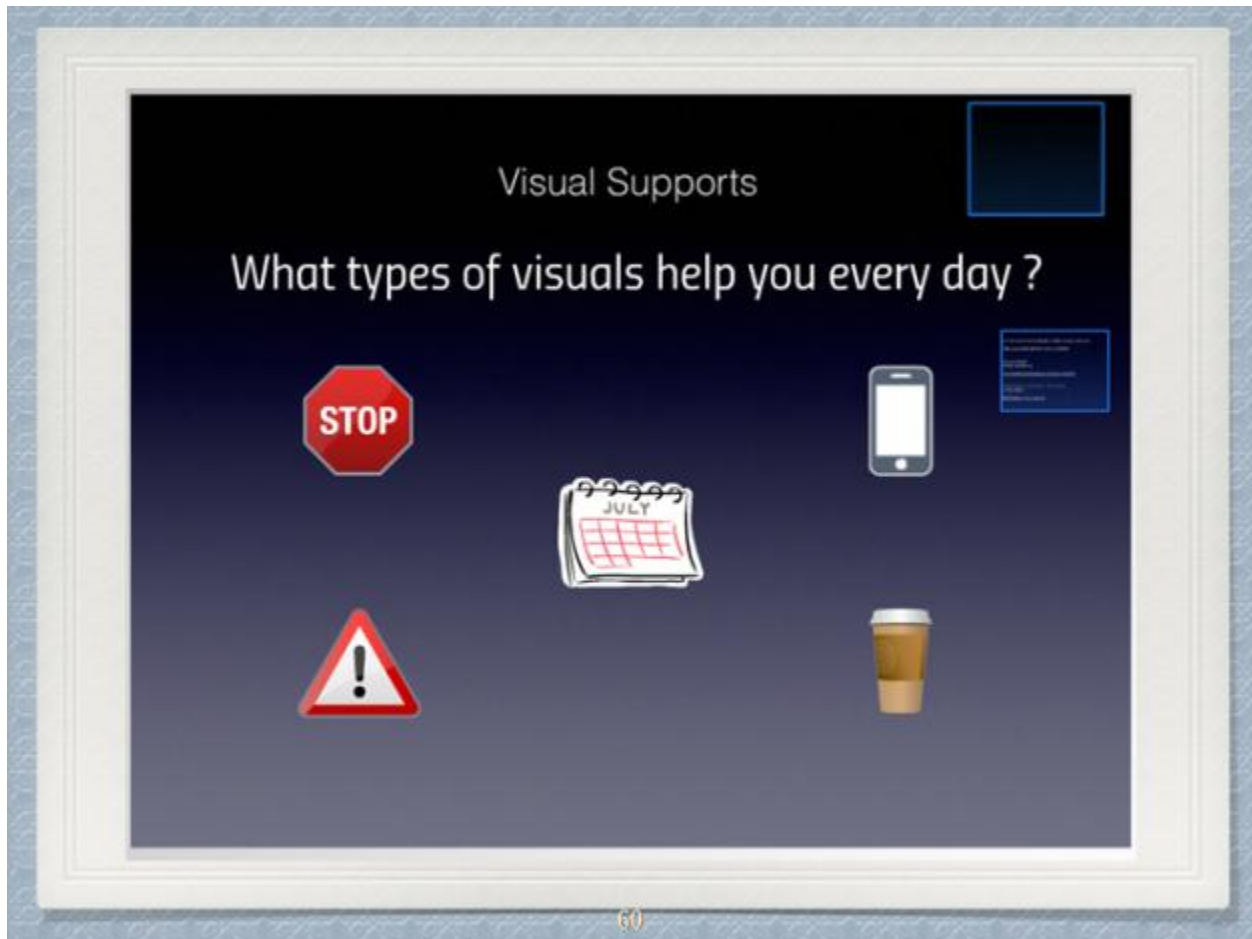


Image 23

Children with ASD may have difficulty processing auditory information, and they often have difficulty interpreting many verbal and gestural cues. Literature both supports and suggests that individuals with ASD “learn more effectively through the use of visuals rather than auditory information” (Mesibov & Shea, 2010, p. 573).

Hierarchy of visuals

- ☐ Objects (real, partial, miniature)
- ☐ Photographs (colour, black and white)
- ☐ Picture symbols or line drawings (colour, black and white)
- ☐ Words
- ☐ Combinations (e.g., words paired with pictures etc.)



Image 24

- Here are some links to free resources to create your own visual supports.

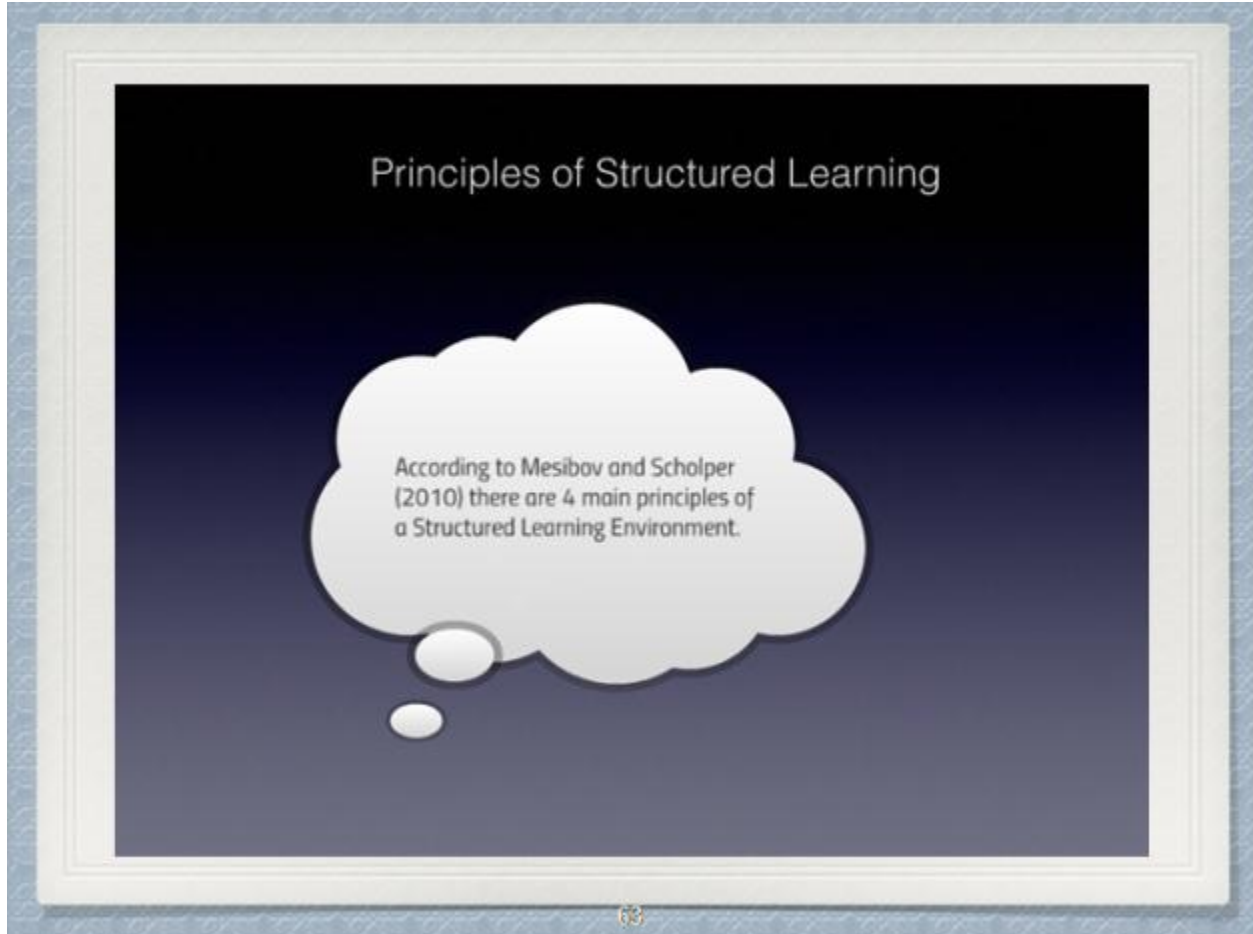


Image 25

- The National Standard Report views Structured Learning Environment as an emerging treatment but some strategies embedded in its principles are already evidence-based.



Image 26

- A Structured Learning Environment: parents look at modifying the environment and children with ASD receive instruction with an emphasis on information provided visually and with “external organizational support” (Hume & Reynolds, 2010, p. 228).
- By utilizing these combined strategies, parents, caregivers and professionals can ensure that children with ASD receive instruction with an emphasis on visual information and modifying the environment with ecological supports.
 - Picture 1 & 2 - Organized home environment. (e.g., orange tablecloth represents game time, cream tablecloth represents dinner time).
 - Picture 3 - Example of a visual schedule (i.e., coloured line drawings).
 - Picture 4- Example of an activity system (i.e., print).
 - Pictures 5 & 6 Examples of how to make activities visually based.

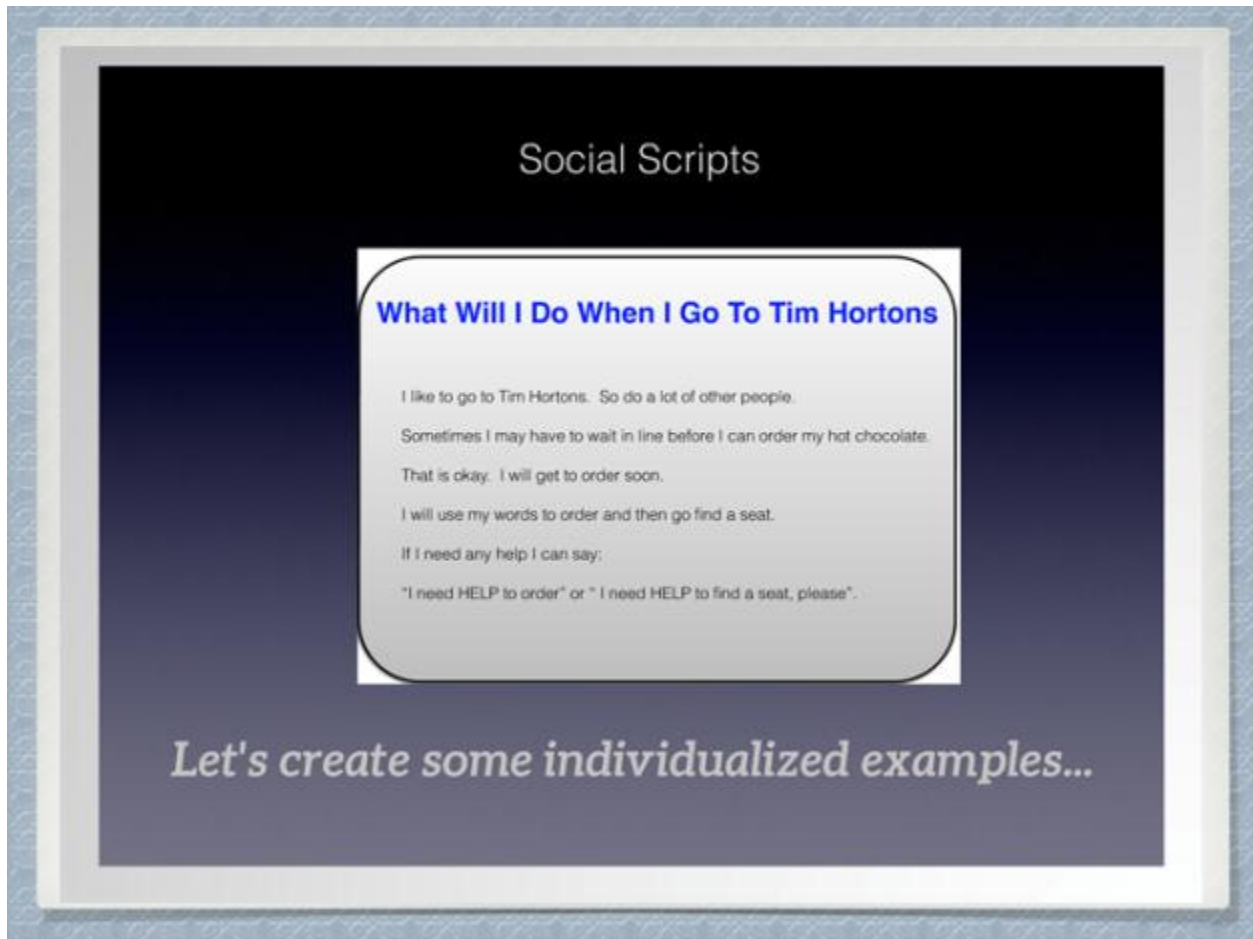


Image 27

Social scripts provide a child with directions on what they can do or say in a specific social situation (National Professional Development Center, 2010).

- *Please bring and show examples you have used or embed them into your presentation*
- *Create some social scripts on smart board and/or chart paper that are individualized to each child's needs.*

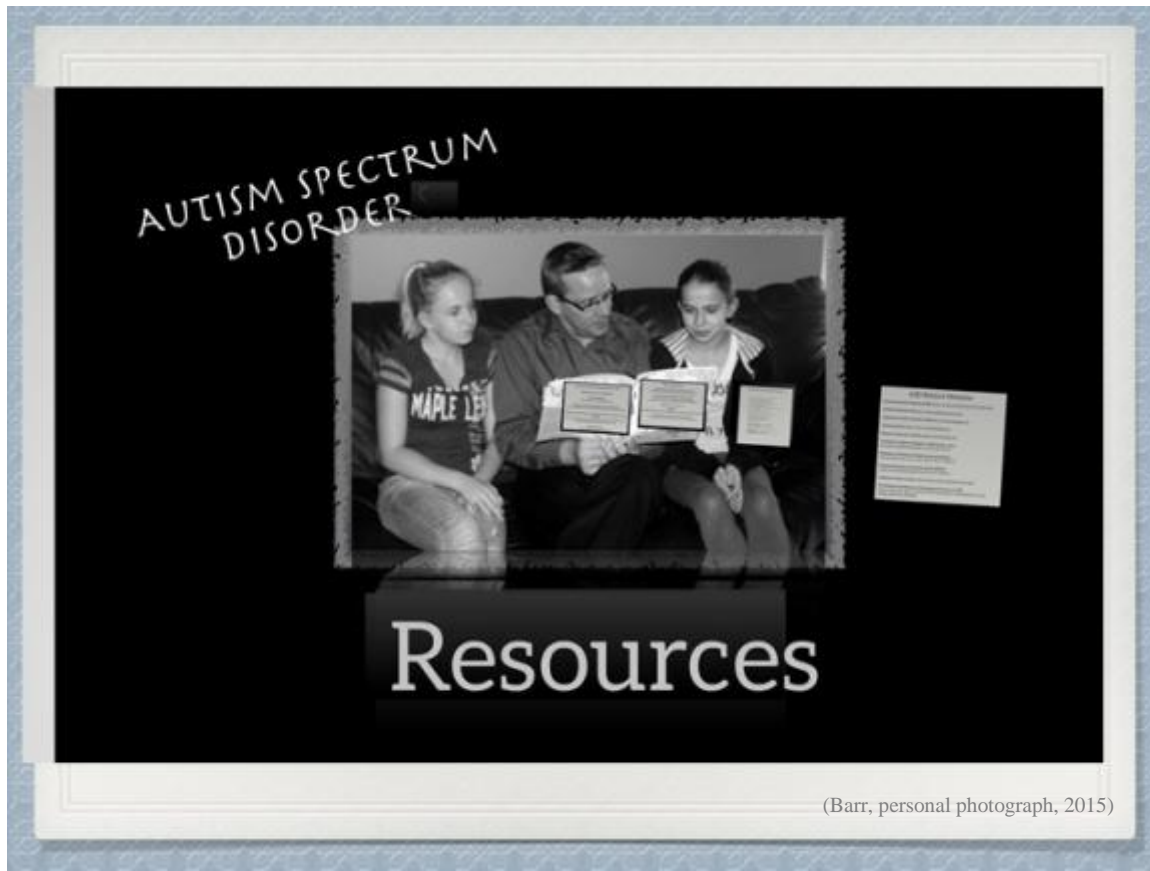


Image 28

The next several slides include resources for families, including local resources for the Hamilton-Wentworth Community.

Please note that yearly updates and revisions may be required.



Image 29

Questions for Audience

- Are you registered with CONTACT Hamilton?
- What supports do you already have in place?

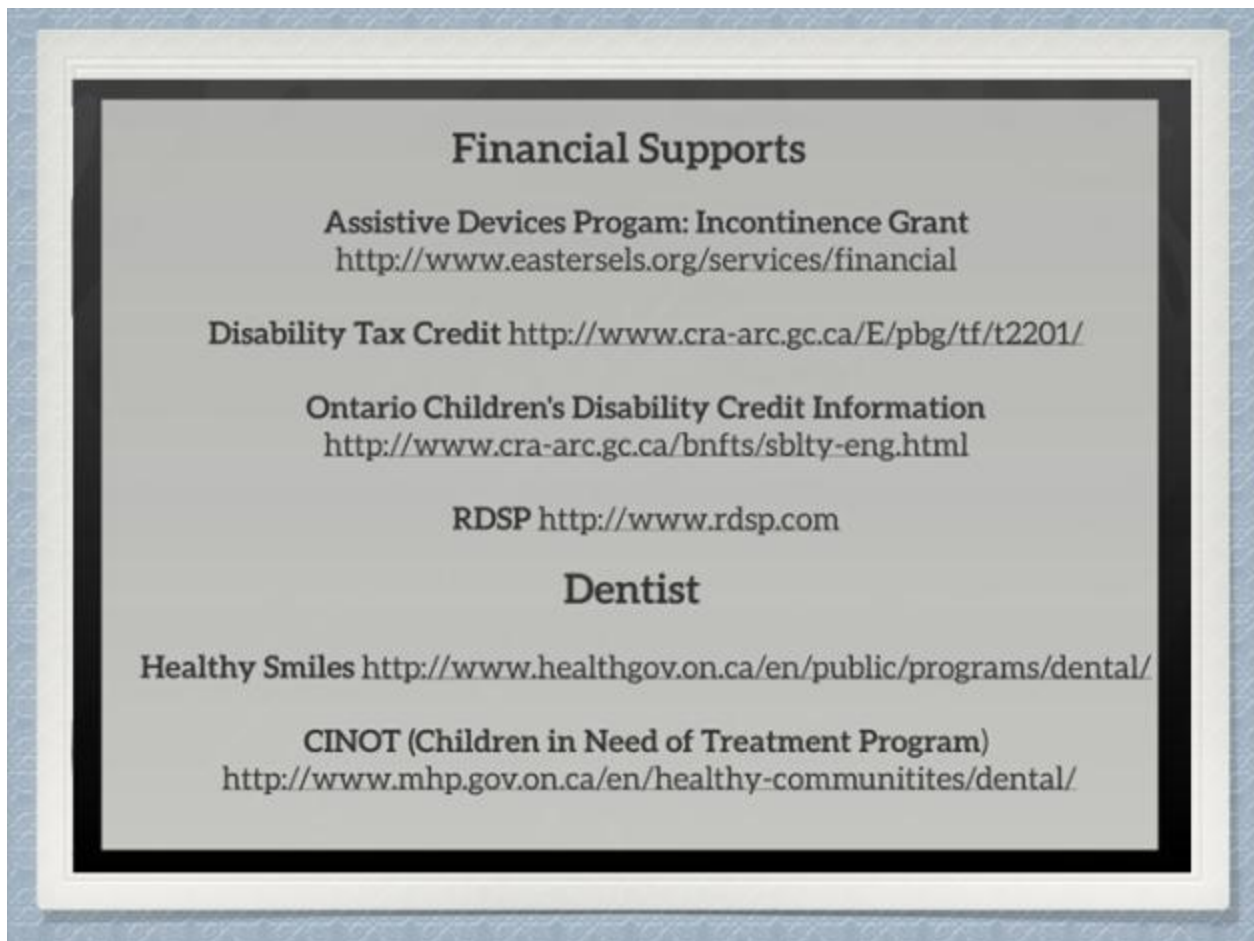


Image 30

Resources that are helpful in every region across Ontario.

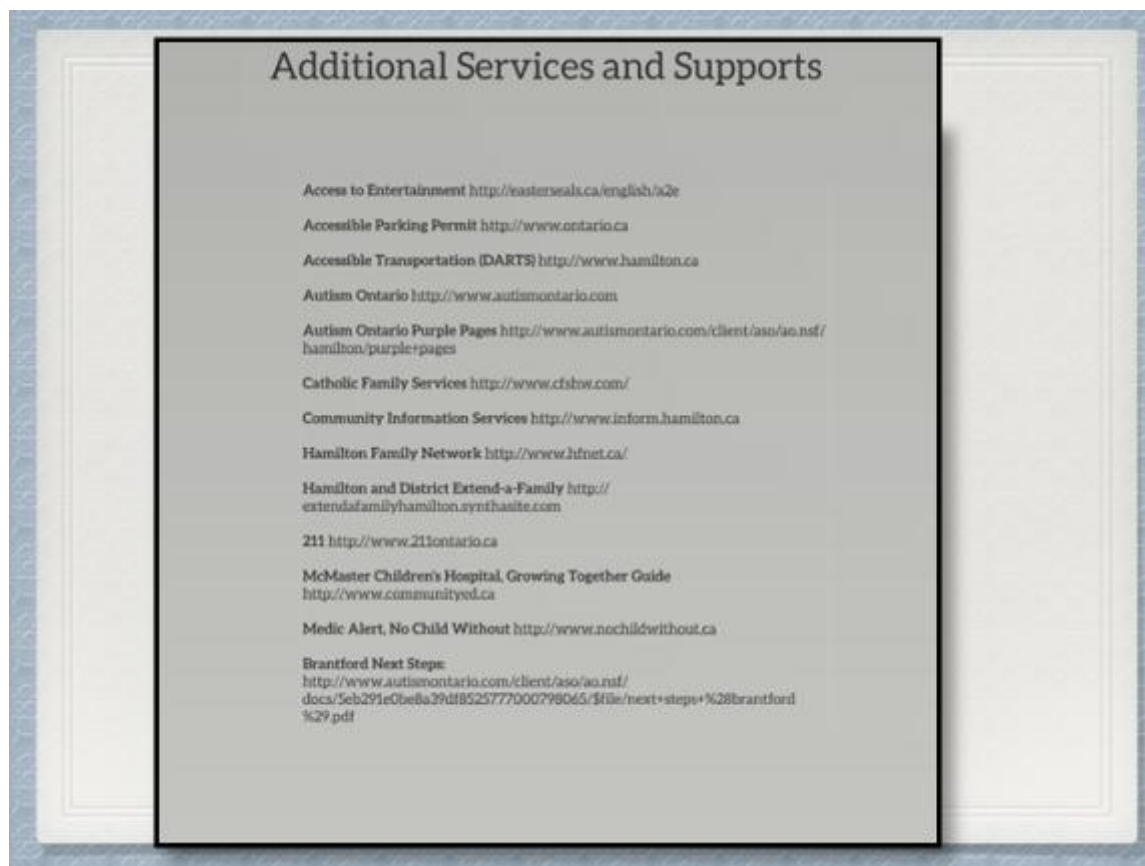


Image 31

Questions for the audience

Are there any additional supports and services that you use? Local and/or regional?

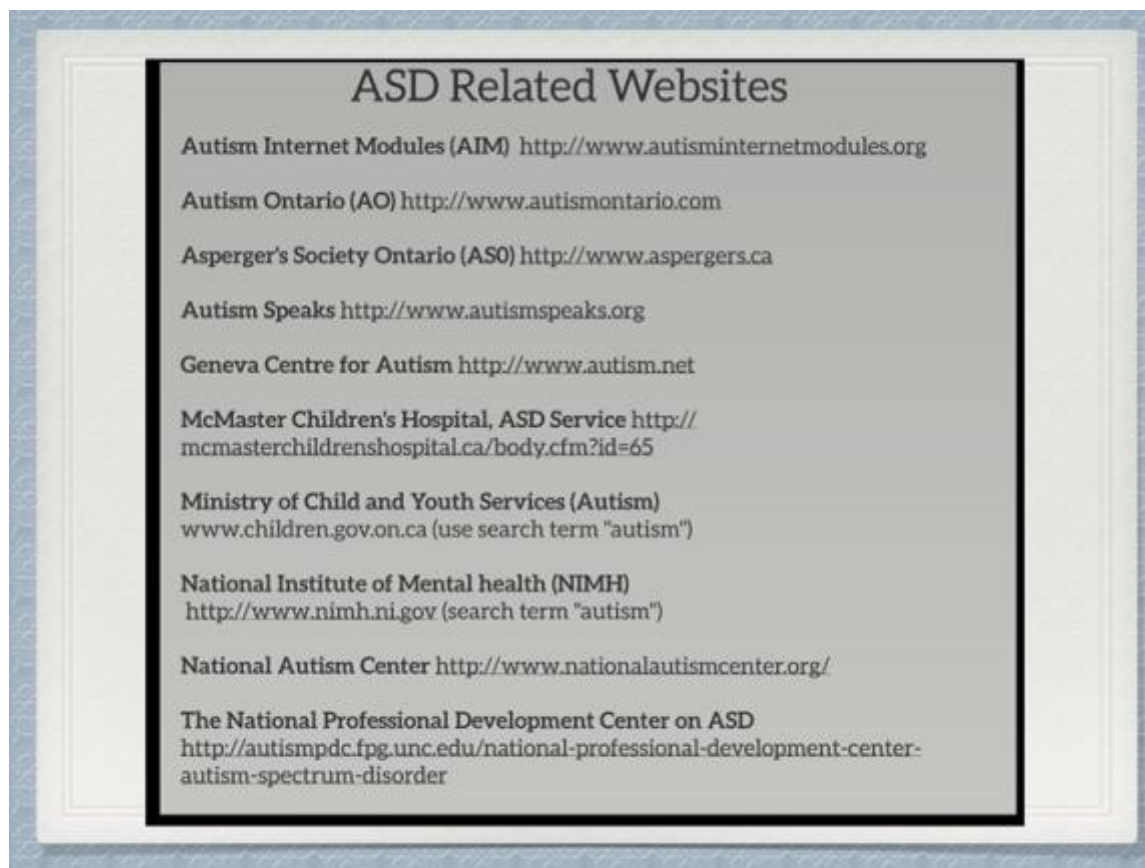


Image 32

Review the ASD related websites that are listed above.

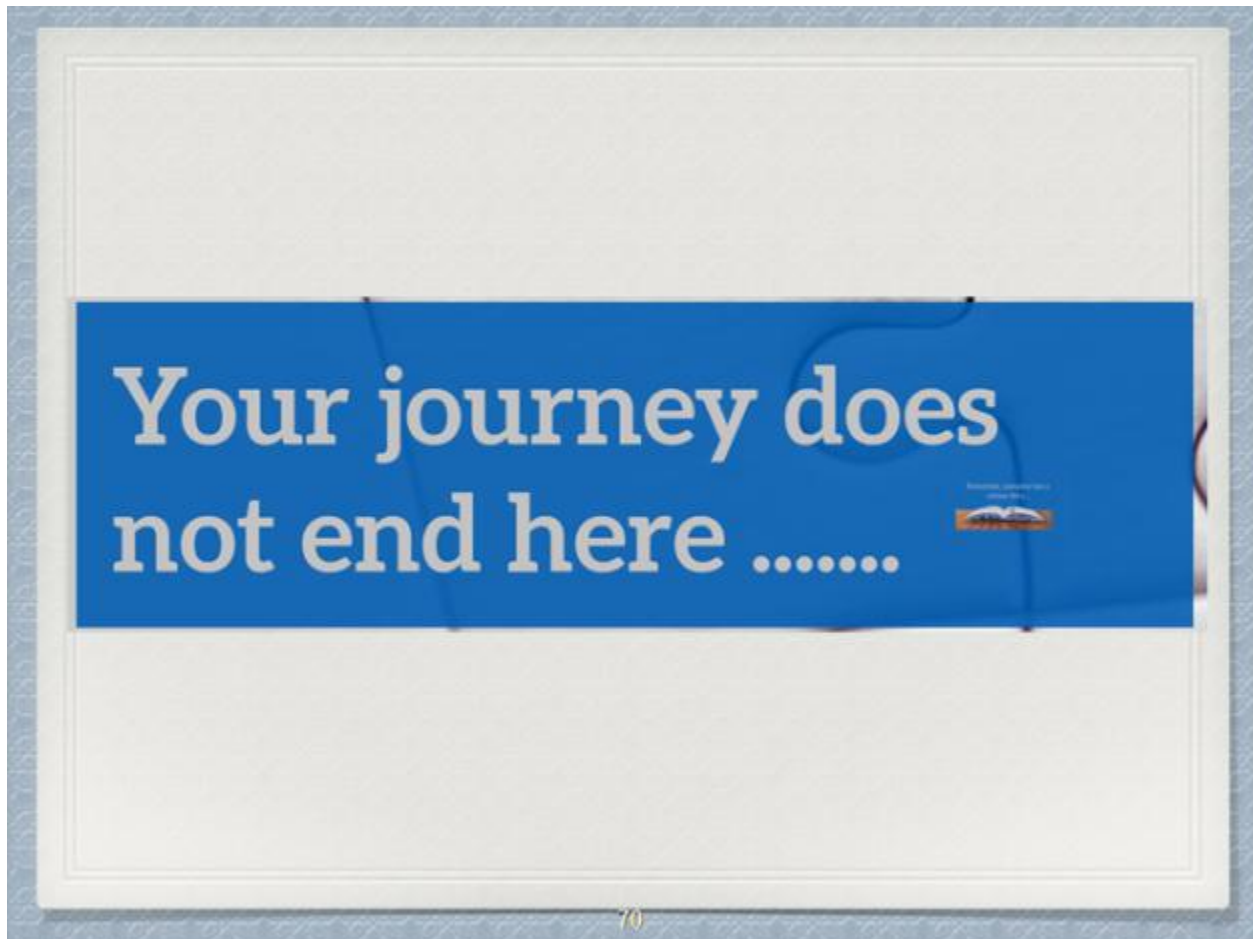


Image 33

There is support available and assistance to help with your journey. This presentation with hyperlinks to resources can be found online and accessed at anytime.

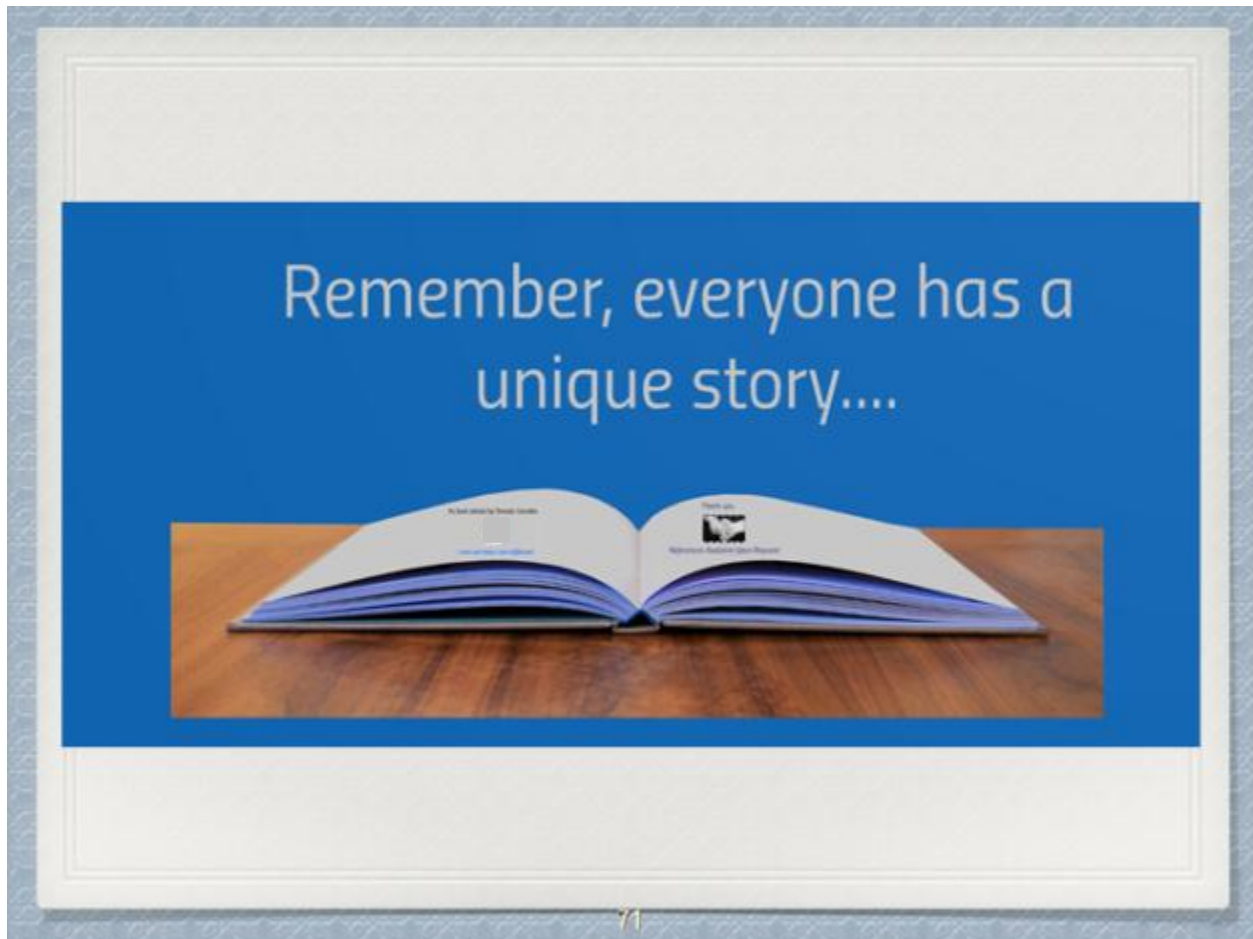


Image 34

All of your stories are unique and special.



Slide 35

As best stated by Temple Grandin "I am not less; I am different" (Butki, 2011).

Question for the audience

What would you like people to know about your child?

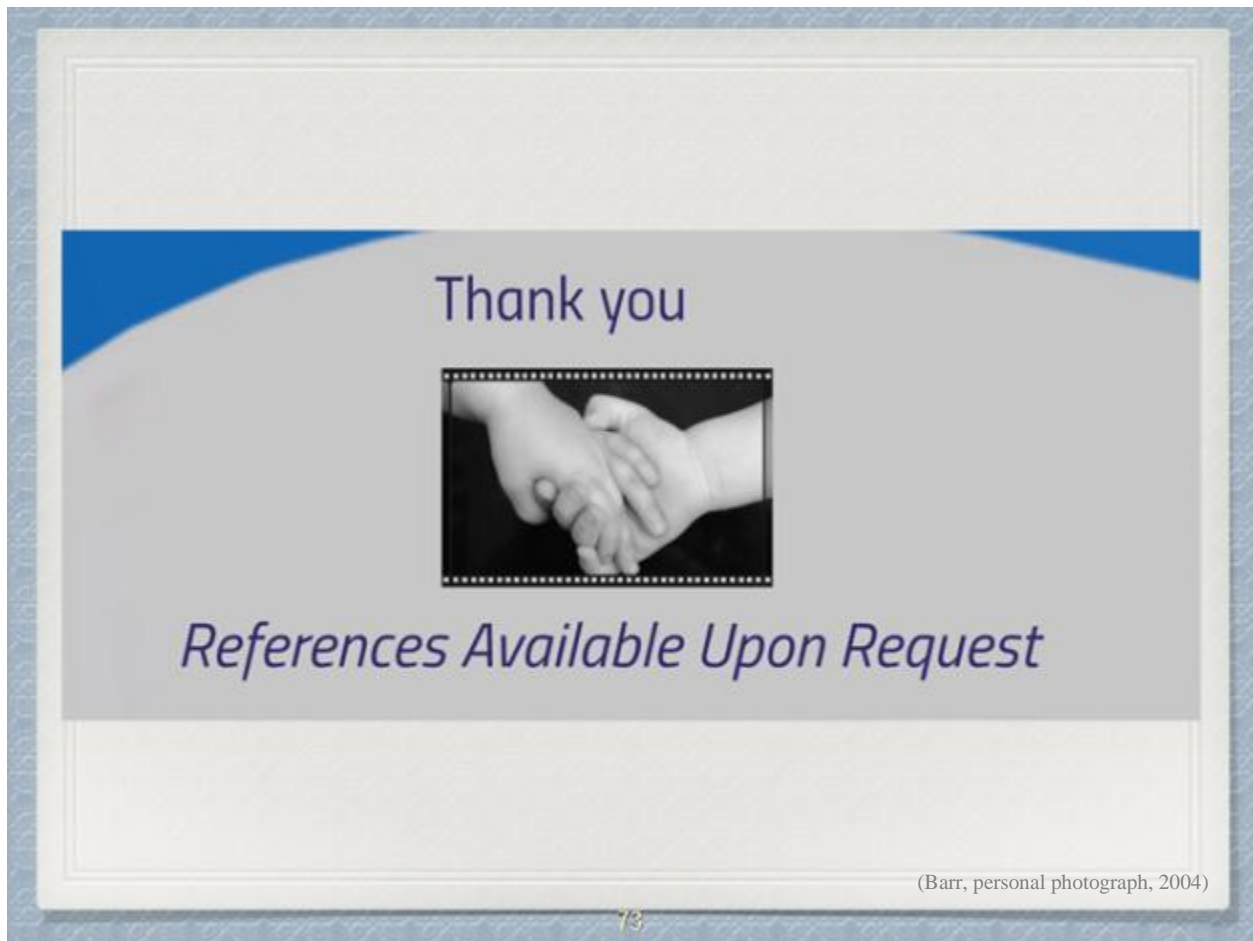


Image 36

Question and Answer

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- American Psychiatric Association. (2012). DSM-5 news release. Retrieved from <http://www.dsm5.org/Documents/12-03%20Autism%20Spectrum%20Disorders%20-%20DSM5.pdf>
- Butki, S. (2010, February 5). My review of HBO Movie: Temple Grandin, “Different but not less.” Retrieved from [http:// http://sbutki.newsvine.com/_news/2010/02/05/3859725-my-review-of-the-hbo-movie-temple-grandin-different-but-not-less](http://sbutki.newsvine.com/_news/2010/02/05/3859725-my-review-of-the-hbo-movie-temple-grandin-different-but-not-less)
- Campbell, R. (2013, April 1). *World autism awareness day video - Autism Ontario- Niagara* [Video file]. Retrieved from <http://www.youtube.com/watch?v=chtqZYnSG1U>
- Center for Disease Control and Prevention (2015). Autism Spectrum Disorder (ASD) Diagnostic Criteria. Retrieved from <http://www.cdc.gov/ncbddd/autism/hcp-dsm.html>
- Hume, K., & Reynolds, B. (2010). Implementing work systems across the school day: increasing engagement in students with Autism Spectrum Disorders. *Preventing School Failure*, 54(4), 228–237.
- Hundert, J. (2009). *Inclusion of students with autism: Using ABA-based supports in general education*. Texas: PRO-ED.
- Maglione, M. A., Das, L., Raaen, L., Smith, A., Chari, R., Newberry, S., & Gidengil, C. (2014). Safety of vaccines used for routine immunization of US children: A systematic review. *Pediatrics*, 134(2), 325-337. Doi:10.1542/peds.2014-1079

- Matson, J. L., Turygin, N. C., Beighley, J., Rieske, R., Tureck, K., & Matson, M. L. (2012). Applied behavior analysis in Autism Spectrum Disorders: Recent developments, strengths, and pitfalls. *Research in Autism Spectrum Disorders*, 6, 144-150.
- Mesibov, G. B., & Shea, V. (2010). The TEACCH program in the era of evidence-based practice. *Journal of Autism & Developmental Disorders*, 40(5), 570-579.
- Nair, A. (2010, September 12). *Temple's speech* [Video file]. Retrieved from <http://www.youtube.com/watch?v=vwJc6HkP8fc>
- National Autism Center (NAC). (2009). *National standards report: Addressing the need for evidenced-based practice guidelines for Autism Spectrum Disorders*. Massachusetts: National Autism Center. Retrieved from <http://www.nationalautismcenter.org/nsp/reports.php>
- National Autism Center (2011, December 7). *Autism manual for parents by the National Autism Center* [Video file]. Retrieved from <http://www.youtube.com/watch?v=ajDvUk4f4Wo>
- National Professional Development Center on Autism Spectrum Disorders. (2010, June 24). *Autism internet modules: Social Narratives and Social Scripts*. Retrieved from <http://www.autisminternetmodules.org>
- Putnam-Spencer, P. (2012, February 19). *Through my eyes—Rosie's story* [Video file]. Retrieved from <http://www.youtube.com/watch?v=g89YYiC7P6Y>
- Reichow, B. (2011). *Evidence-based practices and treatments for children with autism*. New York: Springer Science: Business Media, LLC, 2011.
- Ryan, J. B., Hughes, E., Katsiyannis, A., McDaniel, M., & Sprinkle, C. (2014). Research-based educational practices for students with Autism Spectrum Disorders. *Teaching Exceptional Children*, 47(2), 94-102. doi:10.1177/0040059914553207

Strunk, J. A., Pickler, R., McCain, N. L., Ameringer, S., & Myers, B. J. (2014). Managing the health care needs of adolescents with Autism Spectrum Disorder: The parents' experience.

Families, Systems & Health, 32(3), 328-337. doi:org/10.1037/a0037180

Szatmari, P. (2010). Prevalence and Causes of ASD. [PowerPoint slides]. Retrieved from Autism Spectrum Disorders Service, McMaster Children's Hospital.

Ted Talks. (2010, February 24). *Temple Grandin: The world needs all kinds of minds* [Video file]. Retrieved from http://www.youtube.com/watch?v=fn_9f5x0f1Q

CHAPTER FIVE: SUMMARY, DISCUSSION, AND RECOMMENDATIONS

Navigating Evidence Based Practice for Families and Caregivers of Children with ASD

was created to assist families with access to empirical research and information on treatment choices. Chapter Four presented the facilitator's guide and the URL to the actual presentation created with Prezi (a cloud-based software program). It also coordinated local resources so that families can engage and review the content in an accessible manner. In effort to raise awareness on EBP, an information workshop was developed to support families of children with ASD.

Summary of the Study

My project reviewed the characteristics of ASD and EBP for families and caregivers. It is important to note, that although there are some stand alone resources, we must take into consideration the diverse needs of parents and families of this unique population. On April 2nd, 2015, the National Standards Report (NAC, 2015) was updated with the latest EBP for families, educators, and professionals. This free resource will benefit all parties and help guide decision-making for best treatment for children with ASD. As professionals, we need to engage and educate families while providing accessible up-to-date information on EBPs. There is no single strategy that will work for every child. Each care plan must be individualized and fit family needs along with appropriate clinical assessment and judgment. I want parents to be able to become better informed advocates of their own children and to have the necessary knowledge and resources required to navigate through a complex system as they are going through a difficult time.

Discussion

In order for this to happen, I believe a stand alone document cannot answer families questions or concerns directly which is why I have chosen to create a multimedia presentation

that will allow for a facilitated discussion, clarify questions and concerns while meeting a variety of different learning styles.

The intent of this project was to:

1. Assist families to be better advocates around treatment decisions for their children.
2. To help navigate a local community.
3. To provide evidence based resources.

Parent opinion is important in developing appropriate and effective support systems, not only for children, but for the entire family. According to Weiss, Wingsiong, and Lunskey (2013), the stress associated from having children with ASD is unique and especially salient when compared to families of typically developing children. Ongoing research will continue to be necessary when we consider that the individual needs and best interests of all children with an ASD are of utmost importance. Although there has not been enough research in the area, we must include and be sensitive to cultural norms. Collaboration with families is key in order to create proactive—collaboration with strategies.

Recommendations and Implications

As the prevalence of ASD has increased, it is critical that we need to continually promote EBP for children with ASD. It has been shown that when media reports trends, misinformation can be detrimental to the health of our children with ASD. This makes it vital for families to have access to clear information on EBP. Although we acknowledge that some resources are currently available, they are online or paper resources, which may only benefit independent learners. Also, having resources available in different languages, would address some cultural differences. Currently, interactive webinars are alternative modes that have not been readily

offered or introduced. According to Reichow et al. (2011), we also need to include more ethnic and cultural studies that are not currently found in research. When guiding families through how to choose the best EBP, it is important to consider all available options while focusing on both the individual and family needs.

Implications for Research

This project begins to address the need to increase knowledge about EBPs for families of children with ASD. Future projects and/or research may look at how to share information in the best educational format for families in a way that will meet all learners' needs. It would be of benefit to identify and understand what factors must be taken into account when we review different learning preferences of the families with which we work (Murphy et al., 2011). From my own work experience, I believe a stand-alone document cannot answer families' questions or concerns directly. Given this, I have therefore chosen to create a multimedia presentation that will allow for a facilitated discussion, clarify questions, and address concerns while meeting a variety of different learning styles. Currently, I have found information on EBP to be readily available, but it can be difficult for the average person to circumnavigate. This workshop will help families navigate resources and make current evidence-based information accessible and easy to locate.

Another area that must be reviewed is who is the best individual to facilitate the workshop. As suggested by Murphy, Trembath, Arciuli, and Roberts (2011): "Parents also reported valuing information from 'trusted' sources, such as professionals and fellow parents, over other sources" (p. 126). This leads me to conclude that it would be beneficial for more research to be conducted in this area. Future study also needs to continue reviewing how to locate evidenced based research on the World Wide Web, since it is difficult to locate reputable

resources. Research needs to persist “to identify website characteristics that could lead consumers to high-quality websites with information on ASDs” (Reichow et al., 2011, p. 1270).

Conclusion

As stated by Boyd and Shaw (2010), “the face of ASD is changing and so too must the knowledge base of practitioners working with this population of children” (p. 217). As the prevalence of ASD rises, we will continue to see children diagnosed with ASD. Educators, families, and professionals will need to continue to look towards evidenced-based research to find interventions that will support and encourage our children with autism to become as independent as possible (Hume & Reynolds, 2009). As current research indicates, interventions must meet the need of the child’s specific characteristics of ASD (Fombonne, 2005; Goodman & Williams, 2009; Hume & Reynolds, 2009; Szatmari, 2010). Future research should look at the effectiveness of interventions and continue to research emerging treatments. Researchers also need to look at what is the most effective way to provide professional development to adult learners, especially families, regarding strategies and best practices (Addison et al., 2004). We must continue to find effective ways to enhance the knowledge and understanding of Autism Spectrum Disorders for families, educators, and professionals. As best stated by Temple Grandin, an adult with ASD, “I am different, not less” (Butki, 2011).

References

- Addison, L., Contrucci-Kuhn, S., Lerman, D., & Vorndran, C. (2004). Preparing teachers in evidence-based practices for young children with autism. *School Psychology Review*, 33(4), 510-526.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- American Psychiatric Association. (2012). DSM-5 news release. Retrieved from <http://www.dsm5.org/Documents/12-03%20Autism%20Spectrum%20Disorders%20-%20DSM5.pdf>
- Arthur-Kelly, M., Sigafoos, J., Green, V., Mathieson, B., & Arthur-Kelly, R. (2009). Issues in the use of visual supports to promote communication in individuals with autism spectrum disorder. *Disability and Rehabilitation*, 31(18), 1474-1486.
- Balef, T., Guldberg, K., Jones, G., MacLeod, A., Parsons, S., Prunty, A., (2011). International review of the evidence on best practice in educational provision for children on the autism spectrum. *European Journal of Special Needs Education*, 26(1), 47-63.
- Boyd, B., & Shaw, E. (2010). Autism in the classroom: A group of students changing in population and presentation. *Preventing School Failure*, 54(4), 211-219.
- Butki, S. (2010, February 5). My review of HBO movie: Temple Grandin, "Different but not less." Retrieved from http://sbutki.newsvine.com/_news/2010/02/05/3859725-my-review-of-the-hbo-movie-temple-grandin-different-but-not-less
- Callahan, K., Shukla-Mehta, S., Magee, S., & Wie, M. (2010). ABA versus TEACCH: The case for defining and validating comprehensive treatment models in autism. *Journal of Autism & Developmental Disorders*, 40(1), 74-88.

Center for Disease Control and Prevention (2008). Prevalence of Autism Spectrum Disorders.

Retrieved from <http://www.cdc.gov/features/countingautism/>

Children's Mental Health Ontario (2003). *Evidence-based practices for children and adolescents with Autism Spectrum Disorders: Executive summary of the literature and practice guide*.

Toronto, ON: Dr. Perry and Dr. Condillac.

Cook, B. G., & Odom, S. L. (2013). Evidence-based practices and implementation science in special education. *Council for Exceptional Children*, 79(2), 135-144.

Dunlap, G., Huber, H., Iovannone, R., & Kincaid, D. (2003). Effective educational practices for students with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 18(3), 150-165.

Goodman, G., & Williams, C. (2007). Interventions for increasing the academic engagement of students with Autism Spectrum Disorders in inclusive classrooms. *Teaching Exceptional Children*, 39(6), 53-61.

Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006) Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27, 70-84.

Heflin, L., Hess, K., Ivey, M., Morrier, M. (2008). Autism Treatment Survey: Services Received by Children with Autism Spectrum Disorders in Public School Classrooms. *Journal of Autism & Developmental Disorders*, 38, 967-971.

Hume, K., Loftin, R., & Lantz, J. (2009). Increasing independence in autism spectrum disorders: A review of three focused interventions. *Journal of Autism & Developmental Disorders*, 39(9), 1329-1338.

- Hume, K., & Reynolds, B. (2010). Implementing work systems across the school day: Increasing engagement in students with Autism Spectrum Disorders. *Preventing School Failure*, 54(4), 228–237.
- Hundert, J. (2009). *Inclusion of students with autism: Using ABA-based supports in general education*. Texas: PRO-ED.
- Kalb, C. (2005, February 27) When does autism start? *Newsweek*. Retrieved from <http://thedailybeast.com/newsweek/2005/02/27when-does-autism-start.html>
- Mackintosh, V. H., Myers, B. J., & Goin-Koche, R. P. (2006). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*, 12(1), 41-52.
- Maglione, M. A., Das, L., Raaen, L., Smith, A., Chari, R., Newberry, S. & Gidengil, C. (2014). Safety of vaccines used for routine immunization of US children: A systematic review. *Pediatrics*, 134(2), 325-337. doi:10.1542/peds.2014-1079
- Marder, T., deBettencourt, L. U. (2015). Teaching students with ASD using evidence-based practices: Why is training critical now? *Teacher Education and Special Education*, 38(1), 5-12. doi: 10.1177/0888406414565838
- Matson, J. L., Turygin, N. C., Beighley, J., Rieske, R., Tureck, K., & Matson, M. L. (2012). Applied behavior analysis in Autism Spectrum Disorders: Recent developments, strengths, and pitfalls. *Research in Autism Spectrum Disorders*, 6, 144-150. doi:10.1016/j.rasd.2011.03.014
- McDonald, M. E., Pace, D., Blue, E., & Schwartz, D. (2012) Critical issues in causation and treatment of autism: Why fads continue to flourish. *Child & Family Behaviour Therapy*, 34, 290-304. doi: 10.1080/07317107.2012.732849

- Meadon, H., Ostrosky, M., Triplett, B., Michna, A., & Fettig, A. (2011). Using visual supports with young children with Autism Spectrum Disorder. *Council for Exceptional Children*, 43(6), 28-35.
- Mesibov, G. B., & Shea, V. (2010). The TEACCH program in the era of evidence-based practice. *Journal of Autism & Developmental Disorders*, 40(5), 570-579.
- Mesibov, G. B., Shea, V., & Schopler, E. (2005). *The TEACCH approach to Autism Spectrum Disorders*. New York: Kluwer Academic/Plenum Publishers.
- Mount, N., & Dillon, G. (2014). Parents/experiences of living with an adolescent diagnosed with an Autism Spectrum Disorder. *Educational and Child Psychology*, 31(4), 72-81.
- Murphy A, Trembath D, Arciuli J, Roberts J. (2011). Supporting parents of children with autism spectrum disorders to become informed consumers of evidence on speech pathology practice. *Evidence-Based Communication Assessment & Intervention*, 5(2), 116-129.
- National Autism Center (NAC). (2015). *National standards project: Addressing the need for evidenced-based practice guidelines for Autism Spectrum Disorders, Phase 2*. Massachusetts: National Autism Center. Retrieved from <http://www.nationalautismcenter.org/national-standards-project/phase-2/>
- National Professional Development Center on Autism Spectrum Disorders. (2010, June 24). *Autism internet modules: Social narratives and social scripts*. Retrieved from <http://www.autisminternetmodules.org>
- National Professional Development Center on Autism Spectrum Disorders. (n.d.). *Autism internet modules: Visual supports* [Audio podcast]. Retrieved from <http://www.aim.com>

- Ontario Ministry of Education. (2007). *Effective educational practices for students with Autism Spectrum Disorders*. Retrieved from <http://www.edu.gov.on.ca/eng/general/elemsec/speced/autismSpecDis.html>
- Parsons, M.B., Rollyson, J. H., & Reid, D. H. (2014). Evidence-based staff training: A guide for practitioners. *Behaviour Analysis in Practice*, 5(2), 2-11.
- Powell, S., Thornton, M., Tutt, R., (2006). Educational Approaches in Autism: What We Know about What We Do. *Educational Psychology in Practice*, 22(1), 69-81.
- Reichow, B., Halpern, J. I., Steinhoff, T. B., Letsinger, N., Naples, A., & Volkmar, F. R., (2011). Characteristics and quality of autism websites. *Journal of Autism & Developmental Disorders*, 42, 1263-1274. doi 10.1007/s10803-011-1342-6
- Ryan, J. B., Hughes, E., Katsiyannis, A., McDaniel, M., & Sprinkle, C. (2014). Research-based educational practices for students with Autism Spectrum Disorders. *Teaching Exceptional Children*, 47(2), 94-102. doi:10.1177/0040059914553207
- Sandieson, R. (n.d.). The Pearl Harvesting Search Thesaurus. Retrieved from <http://pearlharvestingsearchthesaurus.wikispaces.com/?responseToken=ca591098e5318d06a355f709c4685b1f>
- Strunk, J. A., Pickler, R., McCain, N. L., Ameringer, S., & Myers, B. J. (2014). Managing the health care needs of adolescents with Autism Spectrum Disorder: The parents' experience. *Families, Systems & Health*, 32(3), 328-337. doi.org/10.1037/a0037180
- Szatmari, P. (2010). Prevalence and causes of ASD. [PowerPoint slides]. Retrieved from Autism Spectrum Disorders Service, McMaster Children's Hospital.
- Torres, C., Farley, C. A., & Cook, B. G. (2012). A Special Educator's Guide to Successfully Implementing Evidence-Based Practices. Teaching Exceptional Children.

- Weiss, J.A., Wingsiong, A., & Lunskey, Y. (2013). Defining crisis in families of individuals with autism spectrum disorders. *Autism, 18*(8), 985-995.
- Yochim, E. C., & Silva, V. T. (2013). Everyday expertise, autism, and “good” mothering in the media discourse of Jenny McCarthy. *Communication and Critical/Cultural Studies, 10*(4), 406-426.